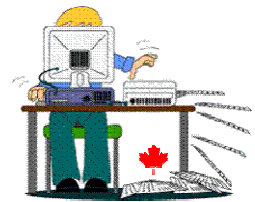


Media Watch...

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

The illness experience: Scroll down to [Specialist Publications](#) and 'The influence of surrogate decision makers on clinical decision making for critically ill adults' (p.10), in *Journal of Intensive Care Medicine*.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Metro News* (Toronto) – 26 December 2013 – '**Assisted suicide debate: Do we need better palliative care?**' Many requests for doctor-assisted suicide are actually pleas for help, said Frank Wagner, a University of Toronto bioethicist and a co-founder of the modern palliative care movement. "Really, they're more cases of depression and unmet pain needs, of being a burden on their family," he said. "When these things fall apart, you'll get requests for physician-assisted suicide." <http://metronews.ca/health/894389/assisted-suicide-debate-do-we-need-better-palliative-care/>
- BRITISH COLUMBIA | CTV News – 24 December 2013 – '**Robert Latimer challenges his travel restrictions in federal court.**' The Saskatchewan farmer was convicted of second-degree murder in 1997 and sentenced to life in prison for killing his severely disabled daughter, Tracy. He was released from prison on day parole in 2008 and granted full parole, with some conditions, in 2010. This past July, the parole board removed one of those conditions but turned down a request by Latimer that he be allowed to travel freely outside the country without having to apply for a limited-time passport. The board's appeal division ruled against Latimer, and he is now asking for a judicial review of the matter in Federal Court in Vancouver. <http://saskatoon.ctvnews.ca/robert-latimer-challenges-his-travel-restrictions-in-federal-court-1.1607141>

Noted in Media Watch, 14 March 2011, #192 (p.2):

- BRITISH COLUMBIA | CTV NEWS – 8 March 2011 – '**Latimer: No regrets about killing disabled daughter.**' The Saskatchewan farmer didn't spend much time thinking about the personal consequences he would face for killing his severely disabled daughter in 1993. Her daily pain and suffering ... were the only things on his mind ... he certainly didn't expect his decision to end Tracy's life would trigger a storm that would envelop his own life... <http://calgary.ctv.ca/servlet/an/local/CTVNews/20110307/latimer-ctv-interview-1100307/20110307/?hub=CalgaryHome>

Cont.

Noted In Media Watch, 28 February 2011, #190 (p.2):

- MANITOBA | *The Winnipeg Free Press* (OpEd) – 26 February 2011 – **'It's time we focused on quality of death.'** The debate over euthanasia is always simmering just below the surface of Canadian society and occasionally it bubbles over, as it is doing today with the release on full parole of Robert Latimer, convicted of the so-called mercy killing of his 12-year-old daughter. <http://www.winnipegfreepress.com/opinion/fyi/its-time-we-focused-on-quality-of-death-116972413.html>

U.S.A.

End-of-life care for an aging LGBT population

NEW YORK STATE | *Advocate* – 27 December 2013 – With the number of self-identified LGBT [lesbian, gay, bisexual, and transgender] adults age 65 or older expected to double by 2030 – from 1.5 million to 3 million, according to the National Resource Center on LGBT Aging – the time has never been more urgent to discuss this silent challenge: How do we meet the unique end-of-life care needs for an aging LGBT population? LGBT seniors are at a greater risk of disability and mental distress than their heterosexual counterparts, and face many barriers to accessing care, notes *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*,¹ a comprehensive 2011 survey conducted in partnership with Services & Advocacy for GLBT Elders. <http://www.advocate.com/health/2013/12/27/end-life-care-aging-lgbt-population>

1. *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*, National Resource Center on LGBT Aging, November 2011. <http://www.lgbtagingcenter.org/resources/resource.cfm?r=419>

Hospice firms draining billions from Medicare

CALIFORNIA | *The Washington Post* – 26 December 2013 – Hospice patients are expected to die: The treatment focuses on providing comfort to the terminally ill, not finding a cure. To enroll a patient, two doctors certify a life expectancy of six months or less. But over the past decade, the number of "hospice survivors" in the U.S. has risen dramatically, in part because hospice companies earn more by recruiting patients who aren't actually dying, a *Washington Post* investigation has found. Healthier patients are more profitable because they require fewer visits and stay enrolled longer. The proportion of patients who were discharged alive from hospice care rose about 50% between 2002 and 2012, according to a *Post* analysis of more than 1 million hospice patients' records over 11 years in California, a state that makes public detailed descriptions and, by virtue of its size, offers a portrait of the industry. The average length of a stay in hos-

pice care also jumped substantially over that time, in California and nationally, according to the analysis. Profit per patient quintupled, to \$1,975, California records show. This vast growth took place as the hospice "movement," once led by religious and community organizations, was evolving into a \$17 billion industry dominated by for-profit companies. http://www.washingtonpost.com/business/economy/medicare-rules-create-a-booming-business-in-hospice-care-for-people-who-arent-dying/2013/12/26/4ff75bbe-68c9-11e3-ae56-22de072140a2_story.html

Specialist Publications

'Office of Inspector General review of Medicare hospice care: Hospices that focus on nursing facility residents' (p.13), in *World Medical & Health Policy*.

N.B. National Hospice & Palliative Care Organization response to *The Washington Post* article: <http://www.nhpc.org/press-room/press-releases/nhpc-responds-washington-post>

Cont.

Noted in Media Watch, 6 May 2013, #304 (p.3):

- **THE WASHINGTON TIMES** | Online – 2 May 2013 – '**Feds sue hospice chain for false Medicare claims.**' The Justice Department filed a lawsuit against the largest for-profit hospice chain in the U.S., charging that the company knowingly submitted false claims to Medicare for services that were not necessary, not actually provided or not performed in accordance with Medicare requirements. <http://www.washingtontimes.com/news/2013/may/2/feds-sue-hospice-chain-false-medicare-claims/>

N.B. A representative list of articles on for-profit hospices noted in past issues of Media Watch appears in this issue of the weekly report (pp.3-4).

Advance medical directives

Texas man wants to end pregnant wife's life support

TEXAS | United Press International – 23 December 2013 – A Texas man said he wants to end life support for his pregnant wife, but state law puts the rights of their 18-week-old fetus above the desires of the mother.¹ Marlise Munoz, 33, became brain dead 26 November when she collapsed from a suspected pulmonary embolism, ABC News reported. Her husband, Erick Munoz, a paramedic, found her on the living room floor of their Tarrant County, Texas, home, and performed CPR before an ambulance arrived. "They don't know how long the baby was without nutrients and oxygen," Erick Munoz said. "But I'm aware what challenges I might face ahead." Erick Munoz said he and his wife, who was also a paramedic, had decided they didn't want to be kept alive by machines before Marlise Munoz fell ill. He said he wants to end her life support. http://www.upi.com/Top_News/US/2013/12/23/Texas-man-wants-to-end-pregnant-wifes-life-support/UPI-59541387805756/?spt=rln&or=1

1. Section 166.049 of the Texas Health & Safety Code reads: "A person may not withdraw or withhold life-sustaining treatment ... from a pregnant patient." And, a health directive under the State's Health & Safety Code reads: "I understand under Texas law this directive has no effect if I have been diagnosed as pregnant." Even if Munoz had completed a DNR order prior to her illness, or pregnancy, the statute would supersede it in order to protect the pregnancy. <http://www.opposingviews.com/i/health/womens-health/texas-law-prohibits-pregnant-woman-marlise-munoz-be-taken-life-support#>

Hospitals must post policies on reproduction, end-of-life care

WASHINGTON STATE | *The Seattle Times* – 23 December 2013 – The horse may be out of the barn on this one, with most hospitals in Washington settled into mergers and affiliations with bigger systems – many of them Catholic, with the attendant restrictions on reproduction and end-of-life care. Even so, the state's Department of Health has hatched new rules requiring that any hospital changing control in the future through a sale, affiliation or merger must seek a Certificate of Need review. Before ownership transfer can take place, facilities must reveal their policies on admission, non-discrimination, end-of-life care, and repro-

ductive health care services to be posted on their own and also on the health department website for public access/comment. <http://blogs.seattletimes.com/today/2013/12/hospitals-must-post-policies-on-reproduction-end-of-life-care/>

Specialist Publications

'The Catholic living will and healthcare surrogate: A teaching document for evangelization, and a means of ensuring spirituality throughout life' (p.10), in *The Linacre Quarterly*.

Cont.

Noted in Media Watch, 16 December 2013, #336 (p.3):

- ABC NEWS | Online – 9 September 2013 – **'Debate over Catholic directives that affect 13% of U.S. hospitals.'** Every Catholic hospital and Catholic healthcare institution must adhere to *Ethical & Religious Directives for Catholic Health Care Services* or risk losing their classification as a Catholic institution. The guidelines cover such issues as end-of-life care... Medical ethicists say that patients should be made aware of how the directives can affect their treatment at Catholic hospitals compared with secular hospitals especially in terms of abortion options or end of life care. <http://abcnews.go.com/Health/catholic-bishops-influence-healthcare-catholic-hospitals/story?id=21123027>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MINNESOTA | *The Star Tribune* (Minneapolis) – 26 December 2013 – **'Minnesota Supreme Court agrees to hear assisted suicide case.'** The fight over which charges – if any – can be pressed against Final Exit Network and two of its members in connection with the 2007 suicide of an Apple Valley woman is headed to the Minnesota Supreme Court. The high court agreed last week to hear Dakota County prosecutors' appeal of an Appeals Court ruling in October that said that the Minnesota law that prohibits advising or encouraging suicide is unconstitutional. The Appeals Court ruling, however, did not dismiss charges of aiding and abetting suicide against the Florida-based group and members Lawrence Egbert and Roberta Massey. <http://www.startribune.com/local/south/237430651.html>

International

Elder care in the U.K.

Elderly want home care but don't discuss needs

U.K. | *The Daily Telegraph* – 26 December 2013 – Nine in 10 people would prefer to be cared for in their own home, research shows, but three quarters do not discuss their desires with their loved ones. The over 50s find it easier to talk about money and funeral plans than where they want to be looked after in their old age. There is a lack of understanding of the options available, experts say, which means decisions only take place when the situation reaches crisis point. More than half of the U.K.'s over 50s have had to organise care for a relative, but a third of them never even asked what their loved one wanted. Of more than 11,700 people questioned, 87% would prefer to be cared for in their own homes if the need arose, while less than one in ten would want to go into a residential care. Further research involving more than 10,200 over 50s found more than three quarters of people do not discuss with their loved ones where they would like to receive care. Men are more likely not to discuss their choices... <http://www.telegraph.co.uk/health/healthnews/10524603/Elderly-want-home-care-but-dont-discuss-needs.html>

Specialist Publications

'Push for palliative care stokes debate' (p.6), in *Bulletin of the World Health Organisation*.

'The development of a 7-day community specialist palliative care service' (p.9), in *International Journal of Palliative Nursing*.

'Economic impact of hospitalisations among patients in the last year of life: An observational study' (p.12), in *Palliative Medicine*.

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.

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

MP makes plea over provision for young people with life-threatening conditions

U.K. (ENGLAND) | *The Bradford Telegraph & Argus* – 25 December 2013 – An MP has sought assurances about provision for the future for young people with life-threatening and life-limiting conditions. Pudsey MP Stuart Andrew asked for the assurances during the Second Reading of the Care Bill: "There are more than 40,000 children and young people aged up to 19 in England who have long-term health conditions which, for most, will eventually end their lives and for which they may require palliative care. Medical advances mean more young people with a range of different conditions are living into adulthood... This represents a 30% increase over ten years. The highest rate of increase is among those aged 16-19, who now account for 4,000 of 0-19-year-olds who need palliative care and it is vital that in such cases, a child's carer's assessments should be undertaken before the young person is 16 and adequate provision for the future is determined."¹
http://www.thetelegraphandargus.co.uk/news/local/localbrad/10899267.MP_makes_plea_over_provision_for_young_people_with_life_threatening_conditions/?ref=nt

1. 18 December 2013, Stuart led a Westminster Hall debate on hospice and palliative care for children and young people: <http://www.bbc.co.uk/democracylive/house-of-commons-25431362>

Of related interest:

- U.K. (SCOTLAND) | *The Herald* (Glasgow) – 28 December 2013 – '**Terminally ill young to spend last moments at home.**' Terminally ill young people are to be given the option to receive end-of-life care in their own homes under a new partnership between two Scottish charities. The service for young people over the age of 16 is designed to avoid the situation faced by many families where youngsters die in unfamiliar beds on hospital wards. It will also help tackle the problems faced by the Children's Hospice Association Scotland [CHAS], which has had to set an age limit on its services. <http://www.heraldsotland.com/news/home-news/terminally-ill-young-to-spend-last-moments-at-home.23041296>

Noted in Media Watch, 13 May 2013, #305 (p.6):

- U.K. (SCOTLAND) | *The Herald* (Edinburgh) – 10 May 2013 – '**Hospice charity sets age limit on services for young people.**' While it does not usually start working with young people of 16 or above, CHAS has never had an age limit on how long existing users can carry on going to its hospices. However, children suffering from conditions such as muscular dystrophy, who were not expected to live past their teens when they were diagnosed, are often living into their 20s and 30s. <http://www.heraldsotland.com/news/health/hospice-charity-sets-age-limit-on-services-for-young-people.21041823>



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>

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-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, exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

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

[Access to hospice and palliative care](#)

Meeting the needs of older adults with serious illness

AGING MEDICINE | Online – Accessed 23 December 2013 – *Meeting the Needs of Older Adults with Serious Illness: Challenges & Opportunities in the Age of Health Care Reform* provides an introduction to the principles of palliative care; describes current models of delivering palliative care across care settings and examines opportunities in the setting of healthcare policy reform for palliative care to improve outcomes for patients, families and healthcare institutions. The U.S. is currently facing a crisis in health care marked by unsustainable spending and quality that is poor relative to international benchmarks. Yet this is also a critical time of opportunity. Because of its focus on quality of care, the Affordable Care Act is poised to expand access to palliative care services for the sickest, most vulnerable, and therefore most costly, 5% of patients – a small group who nonetheless drive about 50% of all healthcare spending. An epiphenomenon of better quality of care, the lower costs associated with palliative care have been observed in multiple studies. *Meeting the Needs of Older Adults with Serious Illness: Challenges and Opportunities in the Age of Health Care Reform*, a roadmap for effective policy and program design, brings together expert clinicians, researchers and policy leaders, who tackle 16 key areas where real-world policy options to improve access to quality palliative care could have a substantial role in improving value. <http://www.springer.com/medicine/family/book/978-1-4939-0406-8>

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 December 2013 – **'Are geriatric medicine fellows prepared for the important skills of hospice and palliative care?'** Many geriatricians care for terminally ill and dying patients, but it is unclear whether the current geriatric medicine fellows receive sufficient training in hospice and palliative care (HPC). A national cross-sectional survey was conducted ... to determine fellows' experience and perceived competency with HPC. Fellows (143 of 298, 48%) and program directors (PDs; 69 of 150, 46%) answered the surveys... Three-fourths of the fellows planned to practice HPC; however, only 35% fellows versus 42% PDs believed that fellows were well prepared in this area. <http://ajh.sagepub.com/content/early/2013/12/23/1049909113517050.abstract>
- *BULLETIN OF THE WORLD HEALTH ORGANISATION*, 2013;91:902-903. **'Push for palliative care stokes debate.'** An estimated 40 million people worldwide need palliative care every year, according to the Global atlas of palliative care which is due to be published by the World Health Organization (WHO) in collaboration with the Worldwide Palliative Care Alliance. Of those, about 21 million people need palliative care at the end of their lives, more than 90% of them as a result of non-communicable diseases. "The majority of people who need palliative care live in low- and middle-income countries where there is little or no access to even basic palliative care services and where the majority die in needless pain and suffering," says Dr. Shanthi Mendis, acting director of the Management of Non-communicable Diseases Department at WHO. "An estimated 42% of countries have no palliative care services whatsoever, while a further 30% have limited service delivery that reaches only a small percentage of the population," Mendis says. <http://www.who.int/bulletin/volumes/91/12/13-021213.pdf>
- *ENFERMERÍA CLÍNICA* | Online – 16 December 2013 – **'Adding value to the care at the final stage of chronic diseases.'** There is a growing number of people with advanced chronic health conditions and with palliative care needs who die without their health and social needs satisfied. This is enough to redefine the traditional models of care in order to focus on the person, rather than on the disease. Taking care of someone is to be concerned about them. And this is related to attitude, commitment and responsibility. In the care of patients who live in a situation of extreme vulnerability, it is possible to help them feel warmth, confident, relieve their suffering, respect their autonomy, and help them find sense and hope, through daily tasks. With gestures, words and facial expressions that go with this care, it is possible to preserve patient dignity. <http://www.sciencedirect.com/science/journal/aip/11308621>

N.B. Spanish language article

Consequences of brain damage in the public debate regarding the end of life. The mediatic prism: A reflection of reality?

ANNALES FRANÇAISES D'ANESTHÉSIE ET DE RÉANIMATION | Online – 21 December 2013
– For the last 20 years or so, conflicts on life-support have become the object of widespread media coverage. By focusing public opinion on the alleged physicians' unreasonable obstinacy, these publicized cases impact social debates on life-support. Via a conducted survey of the various caretakers and families involved in this type of situation, the authors propose an analysis based on the different forms of unreasonable obstinacy. The reasonable or unreasonable nature of treatments can often be perceived differently by physicians, caretakers and families. At least 6 unreasonable obstinacy cases can be brought to light. Publicized cases always involve a conflict between the physicians in charge and the families who view the situation as unreasonable. Nonetheless, evidence shows that in these situations, the roles are often reversed, and the families are the ones demanding the use of unreasonable care. A typical example of this is a recent case that became the object of legal proceedings in France. As it turns out, the publicized filter does not reflect the true reality of cases involving unreasonable care. Specific procedures could aid in notifying the existence of such situations. The role of health care professionals (excluding physicians) appears to play an essential part in preventing these situations from happening.
<http://www.sciencedirect.com/science/article/pii/S0750765813012203>

Reflections on the right to palliative care in Bangladesh: Legal regime revisited

BANGLADESH JOURNAL OF BIOETHICS, 2013;4(3):22-33. Patients with life-limiting illness and their families face many problems and complexities. The gravity of such problem is often escalated with the fact of the patients' deprivation of the proper care as a corollary to their fundamental health rights. The legal aspects of the palliative care thus concern the issues of concentrating more on the rights of the patients in getting relief from sufferings of all kinds, physical, psychological and spiritual. As such, it may include the opportunity of getting legal interventions not only in the way of claiming the protection of palliative care (such as securing access to health and social benefits) but also in the face of dealing with other life-transactions of the patients and their families (such as protecting and disposing of property; planning for children and other dependents). This paper is an attempt to articulate these legal dimensions of the right to palliative care in the context of Bangladesh. <http://www.banglajol.info/bd/index.php/BIOETHICS/article/view/17375>

Of related interest:

- *BANGLADESH JOURNAL OF BIOETHICS*, 2013;4(3):19-24. **'Challenges of palliative care.'** Currently, end of life issues are one of the top ten health care ethics challenges facing the public. There is a new ethical challenge that human life can be ended by a doctor, passively or actively, or a doctor kills the patient. Withholding and withdrawing [life-sustaining treatment], refusal of treatment, physician-assisted suicide, do not resuscitate (DNR) orders, advance directives, consent, and quality of end-of-life care are the main debates in this field. There are many complex ethical issues that can affect patients and families in the health care setting. <http://www.banglajol.info/bd/index.php/BIOETHICS/article/view/17374>

Noted in Media Watch, 11 January 2012, #257 (p.10):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(2):145-149. **""They patiently heard what we had to say ... this felt different to me"": The palliative care needs and care experiences of advanced cancer patients and their families in Bangladesh.** The data fit well within the existing domains of palliative care, as respondents described the family-wide distress and impact of the disease, psychological, physical and social problems. However, the contextual experience of cancer in this setting revealed particular challenges, as respondents described anger, helplessness and mistrust towards existing (non-palliative) healthcare. Poor patient-doctor communication and unmet need for information contributed greatly to these poor experiences. By contrast, experience of palliative care was explained in radically different terms, with a clear shift in the nature of the interaction and resulting care, to bring effective communication and relief from suffering. <http://spcare.bmj.com/content/2/2/145.short>

Undoing the alphabet: A queer fugue on grief and forgiveness

CULTURAL STUDIES – CRITICAL METHODOLOGIES | Online – 16 December 2013 – This essay is written in and as a *queer fugue* – a series of themes and variations on grief, on loss and remembering, on the constitutive and dispossessing dance of relationality, and on the possibilities of becoming and forgiving. It is an essay about public mourning, queer relationships, being undone by death and language, and about making a case for recognizing unrecognized and unspeakable grief. It is an essay that recognizes the debts we owe to those we've lost, celebrates the queer selves and lives we could not do without, and how the words and voices and lives of others who are not acknowledged as fully or equally human are significant and profound. <http://csc.sagepub.com/content/early/2013/11/22/1532708613512260.abstract>

Of related interest:

- *THE FAMILY JOURNAL* | Online – 17 December 2013 – '**A case study of a stepfamily's relationship experiences before and after the death of a custodial biological parent.**' Over the past two decades, the traditional family of mother, father, and shared biological children as the dominant structure of a family has been replaced by the modern family – the stepfamily. The present study explored a stepfamily for the purpose of understanding a phenomenon, that is, a stepfamily's experiences before and after the death of a custodial biological parent. <http://fj.sagepub.com/content/early/2013/12/12/1066480713513556.abstract>

Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers

DEMENTIA, 2014;13(1):96-110. The experience of being a carer of a person with dementia at the end of life is expressed in [the] twelve accounts [presented in this article]. This is a synthesis of the concerns and challenges for carers at the end of life. These accounts are often insightful and provide several views of carers' and professionals' experience. Having a close relationship as a carer gives a unique and poignant view. What emerges from this review is a range of perspectives that provide contrasting views of the heterogeneity of carers and professionals. This may be helpful for professionals and policy makers to consider when planning end-of-life care strategies for people with dementia and insights drawn from hearing directly from carers may be powerful learning tools. <http://dem.sagepub.com/content/13/1/96.abstract>

Of related interest:

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(4):272-288. '**Living in liminality – being simultaneously visible and invisible: Caregivers' narratives of palliative care.**' Research shows palliative care often ends with a death in the hospital due to the heavy burden on the primary caregiver. This study explores the meaning of being the primary caregiver of a close one who is terminally ill and is based on qualitative interviews with primary caregivers of a terminally ill individual at home. A potential impending risk exists of being abandoned when one is the primary caregiver to a close one who is terminally ill. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.846885>

Relatives' participation at the time of death: Standardisation in pre and post-mortem care in a palliative medical unit

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online – 23 December 2013 – Relatives [i.e., study participants] are more often present at the moment of death, while nurses are less present at this moment. Additionally, palliative medical unit nurses use more time to inform and discuss relatives' participation in pre and post-mortem care, as well as making agreements with relatives after death occurs. Important premises for successful standardisation are fostering palliative medical unit nurses' knowledge about various aspects of pre and post-mortem care through regular evaluation and an educational programme providing staff with necessary time, awareness and skills. In addition nurses also require sufficient amount of time in the clinic. [http://www.ejoncologynursing.com/article/S1462-3889\(13\)00160-9/abstract](http://www.ejoncologynursing.com/article/S1462-3889(13)00160-9/abstract)

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

The development of a 7-day community specialist palliative care service

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2013;19(12):612-618 The author worked as a clinical nurse specialist (CNS) in community palliative care in the Central Lancashire area of England when the CNS service was extended to a 9 a.m. to 5 p.m., 7-day service. A project group was set up to canvas some of the key stakeholders for their views on the extension of the service. The group undertook a literature search, a telephone survey of services in other areas that were providing this level of service, and interviews to ascertain the views of district nurses in the locality of the proposed service extension. The extension of service has long been advocated and was one of the key recommendations in the U.K. Department of Health's peer-review process. Such an extension was implemented following the research phase and was then evaluated by the project lead and the community services manager. The extension was found to be effective in the ongoing monitoring and support of patients. Anecdotally, the CNS team also felt it had been proactive in preventing unnecessary hospital admissions, although this specific aspect is difficult to quantify. This article looks at how the service was developed, how it has evolved over time, and how it works today. Consideration is also given to benefits and limitations. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=102429;article=IJPN_19_12_612_618

Of related interest:

- *PROGRESS IN PALLIATIVE CARE*, 2013;21(6):331-336. **'Working together – apart: Exploring the relationships between formal and informal care networks for people dying at home.'** The authors' findings show formal providers [i.e., study participants] are aware and supportive of the vital role informal networks play in the care of the dying at home. A number of barriers to formal and informal networks working together more effectively were identified. <http://www.maneyonline.com/doi/abs/10.1179/1743291X12Y.0000000047>

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.

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3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Saving a life: Balancing risks, harms and benefits in palliative care

JOURNAL OF CLINICAL ONCOLOGY | Online – 23 December 2013 – Pain is one of the most common complaints of patients with advanced cancer, is often moderate to severe, and is usually managed with opioids and adjuvant analgesics; these are effective in the majority of cases. As palliative care becomes increasingly integrated with oncology, patients referred to palliative care specialists live longer, have a better performance status, and are less likely to accept sedation and other adverse events associated with opioids and adjuvant analgesics. In this situation, the possibility of using more invasive palliative interventions may arise. The decision to offer an invasive procedure for symptom control in a patient with advanced cancer is a complex one requiring much deliberation. The burdens, risks, and benefits of the procedure must be communicated and carefully weighed by the physician and the patient. Invasive techniques are part of the palliative care armamentarium, provided the harms and risks do not outweigh the benefits and the intervention is consistent with the patient's goals, priorities, and expectations for their care at this stage of illness. <http://jco.ascopubs.org/content/early/2013/12/23/JCO.2013.53.9338.full.pdf+html>

The influence of surrogate decision makers on clinical decision making for critically ill adults

JOURNAL OF INTENSIVE CARE MEDICINE | Online – 20 December 2013 – Intensive care unit patients rarely have decisional capacity and often surrogates make clinical decisions on their behalf. Little is known, however, about how surrogate characteristics may influence end-of-life decision making for these patients. This study sought to determine how they impact physicians' approach to end-of-life decision making. CPR was considered less appropriate [among study participants] when the surrogate-patient relationship was not close. No other surrogate characteristics examined yielded statistically significant associations. Some surrogate characteristics may modify clinicians' beliefs and practices regarding end-of-life care, suggesting the nuances of the surrogate-physician relationship and clinical decision making for critically ill patients. <http://jic.sagepub.com/content/early/2013/12/19/0885066613516597.abstract>

Disentangling physician-perceived tensions of end-of-life communication

HEALTH COMMUNICATION | Online – 17 December 2013 – Existing literature evidences the centrality of interpersonal communication during end-of-life care, but several barriers currently compromise its effectiveness. One is a common lack of communication skills among physicians in this challenging context. Several strategies have been suggested to enhance end-of-life interactions; however, a solid theoretical framework is needed for the development of effective systematic guidelines and interventions that can facilitate this goal. This study addresses this gap, choosing to focus particularly on the physician's perspective and adds a theoretically framed, empirically grounded contribution to the current literature on the communicative challenges physicians commonly face during end-of-life interactions with patients and their patients' family members. <http://www.tandfonline.com/doi/abs/10.1080/10410236.2013.815533>

Of related interest:

- *THE LINACRE QUARTERLY*, 2013;80(4):317-322. **'The Catholic living will and healthcare surrogate: A teaching document for evangelization, and a means of ensuring spirituality throughout life.'** A truly Catholic living will addresses five key principles: 1) the desire for pain relief; 2) assessing treatments as either ordinary or extraordinary; 3) providing nutrition and hydration; 4) prohibiting euthanasia; and, 5) providing spiritual care. It is individualized and patient-centered and avoids the dangers of a secular living will, which deny patients proper end-of-life care. <http://www.maneyonline.com/doi/abs/10.1179/2050854913Y.000000010>

Cont.

Noted in Media Watch, 21 October 2013, #328 (p.14, under 'Worth Repeating'):

- *ANNALS OF ONCOLOGY*, 2011;22(12):2667-2674. **'The role of relatives in decisions concerning life-prolonging treatment in patients with end-stage malignant disorders: Informants, advocates or surrogate decision-makers?'** This study examines the extent to which relatives of severely ill cancer patients are involved in the decision to limit treatment, their role in communicating patient wishes, and the incidence of and reasons for disagreement with relatives. <http://annonc.oxfordjournals.org/content/22/12/2667.full.pdf+html>

Noted in Media Watch, 4 February 2013, #291 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 January 2013 – **"It hurts to know...and it helps": Exploring how surrogates in the ICU cope with prognostic information.** Surrogates experience a tension between wanting to know what to expect and needing to remain hopeful. This underlies their experience receiving prognostic information and may lead to behaviors that allow continued hope in the face of bad news, including: 1) focusing on small details rather than the big picture; 2) relying on gut instincts or personal beliefs about the patient; 3) seeking more positive prognostic information from other sources, and, for a minority; 4) avoiding or disbelieving prognostic information. Surrogates emphasize the importance of frequent communication and call on physicians to gently help them prepare for the worst and hope for the best. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0331>

Prisoners as hospice volunteers in Poland

MEDYCYNA PALIATYWNA W PRAKTYCE | Online – Accessed 26 December 2013 – Creating programmes combining penitentiary area with hospice-palliative care and voluntary work in different countries is an interesting direction of implementing the ideals of hospice. The first part of this article refers to the description of major initiatives for the reintegration of prisoners through hospice voluntary work. In 2009 Poland was awarded 'The Crystal Scales of Justice' thanks to a programme called WHAT (hospice voluntary work as a tool of acceptance and tolerance for people leaving penal institutions).¹ The project was aimed at social reintegration of prisoners through volunteering for a hospice located outside prison. The results of several years of satisfactory cooperation between the hospice and prison in Gdańsk were passed over to penitentiary counselors and hospice teams in ten cities in Poland. The results of the initial research show that involving prisoners in a hospice team, where they face suffering and dying, improves their psychosocial functioning and the quality of team care. Thanks to the correctional programmes, prisoners are currently working in 29 hospices and more than 70 nursing homes, helping patients in need of instant care. <http://czasopisma.viamedica.pl/mpp/article/view/36628>

1. 'The Crystal Scales of Justice' award, Council of Europe. <http://hub.coe.int/event-files/our-events/the-crystal-scales-of-justice-award>

Contemporary psychological approaches to life at the end of life

OCCUPATIONAL THERAPY IN HEALTH CARE, 2014;28(1):31-41. A holistic, bio-psycho-social-spiritual approach to quality of life near the end of life must address psychological distress of all types, including frank psychopathology, more moderate problems with living, and existential distress. Responding to mental health issues at the end of life requires 1) systematic and careful assessment, and 2) deployment of evidence-based treatments. In recent years, standardized assessment tools have been adapted or developed for use with people who have serious illness, and the same has happened with psychological treatments. Practitioners have several resources available to them. Given their practice orientation centered on meaningful engagement, occupational therapists can play an important role in responding to mental distress in patients with serious illness whose lives are becoming more circumscribed because of their medical condition or because of the mental distress itself. High-quality end-of-life care depends on scrupulous attention to the full spectrum of thoughts, feelings, and behaviors that unfold as death draws near. <http://informahealthcare.com/doi/abs/10.3109/07380577.2013.867090>

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Noted in Media Watch, 12 August 2013, #315 (p.10):

- *PALLIATIVE MEDICINE* | Online – 9 August 2013 – '**Research on psychological and social factors in palliative care.**' A variety of factors ... have presented obstacles to psychosocial research in palliative care. The more recent development of valid and reliable measures of psychological distress and psychological well-being has significantly advanced research in the field. Psychosocial research in palliative care has grown in rigor and volume over the past several decades, and a variety of novel interventions have been developed and evaluated. However, the findings from this research have only begun to have an impact on clinical practice in palliative care. <http://pmj.sagepub.com/content/early/2013/08/07/0269216313499961.abstract>

The Liverpool Care Pathway for the Dying (LCP): Lost in translation and a tale of elephants, men, myopia – and a horse

PALLIATIVE MEDICINE, 2014;28(1):3-7. To reflect on the eruption of articles, opinions, blogs and counter-blogs about the Liverpool Care Pathway for the Dying (LCP) and Baroness Neuberger's Review feels Sisyphean but necessary.¹ While it is time to move on, in doing so, palliative care must think very deeply about what should change about ourselves. This is not to imply that nothing is being done already, to undermine current initiative where it is to be found, nor to preempt the engagement work being undertaken by the Leadership Alliance for the Care of Dying People. (This is an expert group being led by Dr. Bee Wee, National Clinical Director of End of Life Care charged by the Minister & National Health Service (NHS) England to respond to Baroness Neuberger's Review of the LCP.) So we intend through hyperbole to catalyse constructive self-examination and criticism. Disagree, of course, but reflect as you do on why that may be. Metaphorically, it has turned out to be a story about elephants, and in the end, also about a horse. Come the 21st century in the U.K., palliative care was almost mainstream from its birth in the hospice movement. Medicine, generally, was beginning also to assert its clumsy footprint with mixed effect. On the positive side, the specialist palliative medicine training programme had produced a healthy and growing crop of consultants, and many hospitals had palliative care teams. <http://pmj.sagepub.com/content/28/1/3.extract>

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>

Economic impact of hospitalisations among patients in the last year of life: An observational study

PALLIATIVE MEDICINE | Online – 23 December 2013 – The objective of this study [conducted at two large acute hospitals in the North of England, serving contrasting socio-demographic populations] was to determine the extent of potentially avoidable hospital admissions among patients admitted to hospital in the last year of life and to cost these accordingly. Data were collected across a range of clinical, demographic, economic and service use variables and were collected from hospital case notes and routinely collected sources. Palliative medicine consultants identified admissions that were potentially avoidable. Of 483 admissions, 35 were classified as potentially avoidable. Avoiding these admissions and caring for the patients in alternative locations would save the two hospitals £5.9 million per year. Reducing length of stay in all 483 patients by 14% has the potential to save the two hospitals £47.5 million per year; however, this cost would have to be offset against increased community care costs. Reducing length of hospital stay in palliative care patients may offer the potential to achieve higher hospital cost savings than preventing avoidable admissions. Further research is required to determine both the feasibility of reducing length of hospital stay for patients with palliative care needs and the economic impact of doing so. <http://pmj.sagepub.com/content/early/2013/12/23/0269216313517284.abstract>

Cont.

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 23 December 2013 – '**Effectiveness of palliative home-care services in reducing hospital admissions and determinants of hospitalization for terminally ill patients followed up by a palliative home-care team: A retrospective cohort study.**' This study confirms the effectiveness of palliative home care in enabling patients to spend the final period of their lives at home. The services of a palliative home-care team reduced the consumption of hospital resources. This study also provided evidence of some types of cancer (e.g., hematological cancers and hepatocellular carcinoma) being more likely to require hospitalization, suggesting the need to reconsider the pathways of care for these diseases. <http://pmj.sagepub.com/content/early/2013/12/23/0269216313517283.abstract>

Noted in Media Watch, 25 February 2013, #294 (p.5):

- *BMC PALLIATIVE CARE* | Online – 18 February 2013 – '**What is the extent of potentially avoidable admissions amongst hospital inpatients with palliative care needs?**' There is clear evidence that the full range of services required to support people dying at home are far from being implemented, either in England or elsewhere. The authors' findings challenge assumptions that, within the existing configuration of palliative and end of life health and social care services, patients with palliative care needs experience a high level of potentially avoidable hospitalisations. <http://www.biomedcentral.com/content/pdf/1472-684X-12-9.pdf>

Noted in Media Watch, 14 January 2013, #288 (p.12):

- *PALLIATIVE MEDICINE* | Online – 7 January 2013 – '**The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers.**' The following reasons for inappropriate admissions were identified: 1) family carers being unable to cope; 2) the "rescue culture" of modern medicine; 3) the financing and availability of community services; and 4) practice within aged residential care. On the basis of their findings, the authors recommend a shift to the term "potentially avoidable" admission rather than "inappropriate admission." <http://pmj.sagepub.com/content/early/2013/01/04/0269216312469263.abstract>
- *EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 23 December 2013 – '**Dying in hospital: A study of incidence and factors related to hospital death using death certificate data.**' Of all people eligible for palliative care [i.e., study participants], 51% died in hospital, 25% at home, and 24% in long-term care settings. Of those officially living at home at the time of death, hospital death occurred in 60%; of those living in long-term care settings, this was 16%. <http://eurpub.oxfordjournals.org/content/early/2013/12/22/eurpub.ckt209.abstract>

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

Office of Inspector General review of Medicare hospice care: Hospices that focus on nursing facility residents

WORLD MEDICAL & HEALTH POLICY, 2013;5(4):324-334. Since the hospice benefit was introduced into the Medicare program, utilization has increased steeply. Previous research suggested the use of hospice care is growing most rapidly in nursing facilities; however, little was known about the characteristics of the Medicare beneficiaries who receive hospice care in nursing facilities or the hospices that provide care in this setting. A synthesis of research from the U.S. Department of Health & Human Services, Office of Inspector General (OIG) examined Medicare hospice care provided in nursing facilities. Findings suggest some hospices may be seeking out beneficiaries with particular characteristics, including those with conditions associated with longer but less complex care. Such beneficiaries are often found in nursing facilities. By serving these beneficiaries for longer periods, the hospices receive more Medicare payments per beneficiary, which can contribute to higher profits. Recommendations include modifying the payment system for hospice care in nursing facilities and targeting monitoring efforts on certain hospices. <http://onlinelibrary.wiley.com/doi/10.1002/wmh3.70/abstract;jsessionid=2C8324ABF206FB83A6A26A7E9414FDDE.f03t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2013/12/media-watch/>

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

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

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

Asia

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

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

Australia

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

Canada

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

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

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

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

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

ONTARIO | Toronto Central Hospice Palliative Care Network: <http://www.tcpcn.ca/news-events> [Scroll down to 'Media Watch']

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>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *DEATH STUDIES* | Online – 19 December 2013 – '**The Role of and challenges for psychologists in physician assisted suicide.**' Physician assisted suicide (PAS) poses complex legal and ethical dilemmas for practicing psychologists. Since the passage of the Oregon Death with Dignity Act in 1997, Montana and Washington have passed similar legislation. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2013.820228#.UrbmcdJDv8k>

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- *EUROPEAN JOURNAL OF GENERAL PRACTICE* | Online – 20 December 2013 – '**Euthanasia or physician-assisted suicide? A survey from The Netherlands.**' Dutch physicians [i.e., study participants] perceive a difference between euthanasia and PAS [physician assisted suicide]. Although they believe PAS underlines patient autonomy and responsibility, the option of PAS is rarely discussed with the patient. The more psychosocial in nature the patient's suffering, the more physicians choose PAS. In these cases, PAS seems to fulfil physicians' preferences to emphasize patient autonomy and responsibility. Technical problems and unfamiliarity with PAS play a role. Paradoxically, the choice for PAS is predominantly a physician's one. <http://informahealthcare.com/doi/abs/10.3109/13814788.2013.813014>

Worth Repeating

Moving toward peace: An analysis of the concept of a good death

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2006;23(4):277-286. One of the primary outcomes of end-of-life care should be the experience of a good death by the patient and the family. Yet there is no clear, shared understanding of what a good death is. This analysis of the concept of a good death has been guided by Rodgers' evolutionary method of concept analysis.¹ Forty-two articles were analyzed. There was the strong agreement that the concept of a good death was highly individual, changeable over time, and based on perspective and experience. Medical, nursing, and patient perspectives, as well as literature in sociology, include the following attributes of a good death, listed in order of frequency of appearance in the literature: being in control, being comfortable, sense of closure, affirmation/value of the dying person recognized, trust in care providers, recognition of impending death, beliefs and values honored, burden minimized, relationships optimized, appropriateness of death, leaving a legacy, and family care. <http://ajh.sagepub.com/content/23/4/277.short>

1. 'Concepts, analysis and the development of nursing knowledge: The evolutionary cycle,' *Journal of Advanced Nursing*, 1989;14(4):330-335. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2648.1989.tb03420.x/abstract>

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