Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice**, **palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

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

Compiled & Annotated by Barry R. Ashpole

Care planning: Scroll down to <u>U.S.A.</u> and 'Advance directives don't come with directions' (p.4), published in the *Herald-Tribune*, Sarasota, Florida.

<u>Canada</u>

Palliative care must improve, says Health PEI

PRINCE EDWARD ISLAND (PEI) | CBC News – 23 June 2012 – Delegates at the P.E.I. Palliative Care Conference heard that there are not enough services available to alleviate the suffering of the dying. "We're facing a tremendous increase in the amount of people that are going to die in Canada," said Dr. Mireille Lecours, Medical Director for palliative care. "We need to face that and increase capacity." Fewer than 30% of dying Canadians are receiving palliative care. That statistic is about the same on P.E.I. <u>http://www.cbc.ca/news/canada/prince-edward-island/story/2012/06/23/pei-palliative-care-future-584.html</u>

Community-integrated palliative care

\$3 million funding to help palliative care

MANITOBA | *Portage Daily Graphic* (West Portage la Prairie) – 20 June 2012 – A recent funding announcement of a large donation to benefit palliative care nationally is positive news to local providers in the Portage la Prairie area. The federal government reported a total of \$3 million was to be given out to Canadian Hospice Palliative Care Association for a three-year initiative. The project will involve developing community-integrated palliative care models. "It will be interesting to see how it will benefit the programs across the country," said Pat Chimney, volunteers' co-ordinator with Sunset Palliative Care, based in Portage la Prairie. She added anything that can benefit palliative care services is always appreciated. "The need is immense," Chimney said. http://www.portagedailygraphic.com/ArticleDisplay.aspx?e=3588173

Of related interest:

 ONTARIO | Sun Times (Owen Sound) – 20 June 2012 – 'Baby boomers driving need for palliative care.' Grey-Bruce has spent too much time without organized integrated end-of-life care – largely because of petty disagreements – and it's time to move forward, says a palliative care expert. Good palliative care needs to be integrated among hospitals, home care services and possibly a residential hospice. <u>http://www.owensoundsuntimes.com/ArticleDisplay.aspx?e=3588135</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

BRITISH COLUMBIA | Chronicle-Herald (Halifax, Nova Scotia) – 20 June 2012 – 'Conservatives not eager for suicide debate.' A fragile two-decade-old Supreme Court consensus that may not have survived the test of time is all that now stands between Canada's MPs and a debate they don't want on the right to an assisted suicide. Last week, the British Columbia Supreme Court ruled that the prohibition on doctor-assisted suicide was unconstitutional. Justice Lynn Smith gave Stephen Harper's government a year to come up with a constitutionally friendly version of the legal dispositions on the matter. If only because it amounts to their last best hope of dodging a divisive national social policy debate, the federal Conservatives will almost certainly appeal the finding. At a minimum, taking it up to the Supreme Court would allow the government to buy time. In the best-case scenario for the ruling Conservatives, the B.C. ruling could be overturned. The last time the top court pronounced on the issue, it declined to pry open the door to assisted suicide. But that was in 1993 and the ruling split the court five to four. http://thechronicleherald.ca/opinion/109051-conservatives-not-eager-for-suicide-debate

Of related interest:

- HUFFINGTON POST | Online commentary 19 June 2012 'Don't speak legalese? Here's what the assisted suicide ruling really means.' As is common in cases of this nature where legislation has been found to be constitutionally inoperative, Madam Justice Smith suspended the effect of her declaration for a period of one year to enable Parliament to respond and to perhaps change the legislation to accord with the Court's findings. However, Madam Justice Smith also granted Taylor a constitutional exemption that will enable her to access physician-assisted suicide under certain strict conditions if the need arises... http://www.huffingtonpost.ca/ron-skolrood/bc-assisted-suicide-bed http://www.huffingtonpost.ca/ron-skolrood/bc-assisted-suicide-bed http://www.huffingtonpost.ca/ron-skolrood/bc-assisted-suicide-bed http://www.huffingtonpost.ca/ron-skolrood/bc-assisted-suicide-bed http://www.huffingtonpost.ca/ron-skolrood/bc-assisted-suicide-bed http://www.huffingtonpost.ca/ron-skolrood/bc-assisted-suicide-bed
- GLOBE & MAIL | Online article 19 June 2012 'The importance of picking a vocabulary for dying.' Physician-assisted suicide? Physician-enabled death? Physician-hastened death? Euthanasia? Voluntary euthanasia? Rational suicide? Suicide? Mercy killing? State-sanctioned murder? Death with dignity? And there are many more variations, each loaded with legal and moral bag-gage. The language we choose tends to reflect where we stand on the underlying question of whether grievously and irremediably ill people should have the right to choose to end their lives rather than let an illness take its course. Ultimately, the fundamental legal issue is choice: Do individuals have control over their bodies in death as in life? There are obvious parallels with the abortion debate. http://www.theglobeandmail.com/news/politics/picking-a-vocabulary-for-dying/article4338418/

<u>U.S.A.</u>

Inmates help care for sick, dying prisoners

NEW YORK STATE | *Observer-Dispatch* (Utica) – 25 June 2012 – Mohawk Correctional Facility inmates Daniel Jenkins and Albert Nieves are part of the state's strategy to meet the health care needs of its aging prison population. Both men volunteer as palliative aides, spending time with and helping dying and incapacitated inmate patients at the Walsh Regional Medical Unit, a maximum security health facility within the medium-security Mohawk prison. The state's five regional medical units offer either hospice or palliative care to their patients. "From a moral and a kindness issue, the idea of being very sick in a corrections environment, being terminally ill in a corrections environment and dying in a corrections environment has got to be a very difficult situation," said Dr. Carl Koenigsmann, deputy commissioner and chief medical officer of the state Department of Corrections & Community Supervision. <u>http://www.uticaod.com/news/x2102585578/Inmates-help-care-for-sick-dying-prisoners</u>

N.B. Articles and reports focused on the provision and delivery of end of life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.13.

Eco-friendly hospice house provides resort-style care

OHIO | WKYC News (Cleveland) – 23 June 2012 – A new, eco-friendly hospice facility in Westlake will give patients state-of-the-art care in an atmosphere that feels like a spa resort. Built with \$19 million in donations, the Ames Family Hospice House is designed for symptom management and short-term care for seriously ill patients and their families. Exercise and meditations rooms, a spa, wooded courtyards, and music, art and pet therapies all provide holistic care beyond typical medical treatments. The healthcare center's 32 private suites are equipped to handle even the most complex cases, including pediatric and HIV/AIDS patients. Using several green technologies throughout the building, the new center includes energy efficient features and rain water recycling for the gardens on its 30-acres of land. <u>http://www.wkyc.com/news/article/249609/3/Eco-</u> friendly-hospice-house-provides-resort-style-care

Study: 'Death panel' myth persists; one-third of Americans still believe false claim

COLORADO | KUNC 95.1 News (Greeley) – 19 June 2012 – As the [U.S.] Supreme Court is about to rule on the constitutionality of the health care law [Affordable Health Care Act], one-third of Americans are worrying about a part of the legislation that isn't there. A Kaiser Family Foundation's tracking poll found ... that 36% of respondents erroneously believe that the law "would allow a government panel to make decisions about end-of-life care for people on Medicare." Another 20% said they are not sure whether it does. <u>http://www.kunc.org/post/study-death-panel-myth-persists-one-third-americans-still-believe-false-claim</u>

Of related interest:

- ASSOCIATED PRESS | Online report 19 June 2012 'Study shows health care opponents won in media.' Opponents of President Barack Obama's health care plan decisively beat supporters in getting their message across through the media.¹ Opponents won, in part, because their positions were sharper and easier to understand. <u>http://articles.boston.com/2012-06-</u> <u>19/ae/32319753 1 health-care-death-panels-supporters</u>
 - 'What Americans Learned from the Media About the Health Care Debate,' The Pew Research Center's Project for Excellence in Journalism, June 2012. <u>http://www.journalism.org/commentary_backgrounder/ho</u> w media has covered health care debate
- CNN | Online report 21 June 2012 'Advocacy group: 26,000 die prematurely without health insurance.' 500 Americans die every week and approximately Americans 2,175 die each month, due to lack of health insurance."¹ The Affordable Care Act was passed by Congress to address an American tragedy and an American shame," said Ron Pollack, Executive Director Families USA. <u>http://thechart.blogs.cnn.com/2012/06/20/families-usa-says-</u> 26000-die-prematurely-without-health-insurance/
 - 1. 'Dying for Care,' Families USA, June 2012. http://familiesusa2.org/assets/pdfs/Dying-for-Coverage.pdf

The care quandary: Six months. \$1.2 million. Was it worth it?

MISSOURI | St. Louis Today – 24 June 2012 – With the fate of the national health care overhaul now in the hands of the Supreme Court, many experts agree that the ethical and financial dynamics of dying should remain at the center of the national health debate. Yet few politicians, bureaucrats, insurers and doctors dare even to discuss it. And no one seems to have a clue as to how our society can afford to pay national health costs that approached \$2.6 trillion in 2010 - a tenfold increase since 1980, according to the Centers for Medicaid and Medicare Services. http://www.stltoday.com/news /local/the-care-guandary-sixmonths-million-was-it-worthit/article d9310228-bd52-11e1-b34e-001a4bcf6878.html

Advance directives don't come with directions

FLORIDA | Herald-Tribune (Sarasota) - 18 June 2012 – Robert H. Laws, a retired judge in San Francisco [California], and his wife, Beatrice, knew it was important to have health care directives in place to help their doctors and their two sons make wise medical decisions should they ever be unable to speak for themselves. With forms from their lawyer, they completed living wills and assigned each other as health care agents. They dutifully checked off various boxes about not wanting artificial ventilation, feeding tubes and the like. But what they did not know was how limiting and confusing those directions could be. For example, Laws said ... he'd want to be put on a ventilator temporarily if he had pneumonia and the procedure would keep him alive until antibiotics kicked in and he could breathe well enough on his own. What he would not want is to be

on a ventilator indefinitely, or to have his heart restarted if he had a terminal illness or would end up mentally impaired. Nuances like these ... escape the attention of a vast majority of people who have completed advance directives, and may also discourage others from creating directives in the first place.<u>http://health.heraldtribune.com/2012/0</u> <u>6/18/advance-directives-dont-come-withdirections/</u>

Specialist Publications

Of particular interest:

'Challenges of do-not-attempt-resuscitation orders,' (p.10), published in the *Journal of the American Medical Association*

Of related interest:

NEW YORK | Yeshiva World News – 18 June 2012 – 'Amendment to health care law to protect patients.' An amendment to the [State's] Public Health Law [ensures] patients in the end stages of life will be informed of all their options, including their right to ongoing medical treatments as well as palliative care. Under the earlier version ... health care providers were required to inform such patients of their right to palliative care – but not of the option of ongoing, aggressive medical treatment of their condition. http://www.theyeshivaworld.com/news/General+News/130742/Assemblyman-Goldfeder-Amends-Health-Care-Law-to-Protect-Patients.html

Loneliness bodes poorly for a healthy old age

NATIONAL PUBLIC RADIO | Online report – 18 June 2012 – Loneliness in older people can predict declines in health and an increased risk of death, according to findings [of a recent study].¹ People over 60 who felt lonely had a 45% higher risk of death than those who weren't lonely, the six-year-long study found. In absolute terms, the risk of death was about 23% for the lonely people and 14% for those who weren't. The lonely people in the study were also more prone to have limited mobility and face greater difficulty performing basic tasks like grooming and housekeeping. On that score, about a quarter of lonely people were likely to develop trouble compared to about 13% who weren't lonely. <u>http://www.npr.org/blogs/health/2012/06/18/155303522/lonelinessbodes-poorly-for-a-healthy-old-age</u>

1. 'Loneliness in older persons: A predictor of functional decline and death,' *Annals of Internal Medicine*, June 2012. <u>http://archinte.jamanetwork.com/article.aspx?articleid=1188033</u>

From Media Watch ('Worth Repeating'), 21 November 2011:

 AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2007;24(5):399-407. 'The dying ... and how they cope with loneliness.' <u>http://ajh.sagepub.com/content/24/5/399.short</u>

International

Elderly care: Government delays threatening future of homes report warns

U.K. | Daily Telegraph - 23 June 2012 - Private operators are under renewed pressure after the report showed that the fees they receive from councils to look after elderly people have risen slower than inflation for the third year in a row. Age UK said the figures from the health analysts Laing & Buisson showed that care for the elderly was now being "cut to the bone" and warned that the crisis is "deepening by the day." A promised Government white paper on overhauling the care system has been repeatedly delayed. It is now expected in the next few weeks. Meanwhile behind-the-scenes cross party talks intended to thrash out a new way to fund care for Britain's ageing population, following a landmark report by the economist Andrew Dilnot,¹ are believed to have stalled. http://www.telegraph.co.uk/health/healthnews/9350169/Elderl v-care-Government-delays-threatening-future-of-homesreport-warns.html

Specialist Publications

Of particular interest:

'Hiring and screening practices of agencies supplying paid caregivers to older adults' (p.10), published in the Journal of the American Geriatrics Society

1. *Fairer Care Funding*, Report of the Commission on Funding of Care & Support, July 2011 (noted in Media Watch, 11 July 2011). <u>https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf</u>

Getting care right at the end of life

U.K. | *Local Government Chronicle* – 21 June 2012 – When 24/7 community nursing is not in place, family carers are left with no choice but to dial 999 when incidents occur. People are then unnecessarily admitted to hospital, often never to leave. If the right support is available, 'bad' deaths can be avoided. Social care is another service crucial to supporting people to be cared for at home at the end of life. It provides much-needed help for families who tell us that looking after a loved one during their final months can take a significant toll. However, we know that many people currently cannot access the social care they and their families need. The Independent Palliative Care Funding Review recommended that the social care means-test be scrapped for those in the final months of life.¹ This would help integrate the health and social care systems at end of life, enabling more people to be discharged from hospital quickly and cared for at home. http://www.lgcplus.com/topics/health/getting-care-right-at-the-end-of-life/5044884.article?blocktitle=Latest-Opinion&contentID=5828

 'Funding the Right Care and Support for Everyone Creating a Fair and Transparent Funding System,' Independent Palliative Care Funding Review, July 2011 (noted in Media Watch, 4 July 2011). <u>http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_133105</u>.pdf



Barry R. Ashpole

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

End-of-life care for lesbian, gay, bisexual and transgender people

U.K. | National Health Service – 21 June 2012 – Lesbian, gay, bisexual and transgender (LGBT) people are at risk of not receiving high quality end of life care services, with many facing problems in terms of being treated with dignity and respect. A new guide seeks to address this.¹ Accurate numbers of LGBT people in the U.K. are hard to establish, with official figures ranging from 750,000 to 3.6 million. <u>http://www.endoflifecareforadults.nhs.uk/publications/rts-lgbt</u>

 'The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people,' National End of Life Care Programme, June 2012. <u>http://www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_LGBT_Route_to_Success_web_.pdf</u>

N.B. See Media Watch, 21 May 2012 (p.9) for a listing of articles, reports, etc., on the provision and delivery of end-of-life care for lesbian, gay, bisexual and transgender people.

The cost of hope and the price to be paid for refusing to accept death

IRELAND | *Irish Examiner* (Cork) – 19 June 2012 – The doctor stared at ... [Amanda Bennett] ... baffled to find that, despite the overwhelming evidence to the contrary, this self-evidently intelligent woman believed her husband was facing difficult, but not impossible odds. She was wrong. Within days ... [he] ... was dead. The unthinkable had happened. Unthinkable because his wife had not only refused to consider death as a possibility, but had done her best to stop her sick husband thinking about it in that light either. Returning home after a previous hospitalisation, he had taken out a pad and drawn a line down the middle, making a list of his possessions and deciding on paper whether they were simply to be thrown out or given to a named friend or relative. When she found him at the task, she yelled at him that he wasn't going to die and discouraged him fairly vividly from continuing his list-making. It wasn't the first time she had rejected, on his behalf, the possibility of dying when he seemed to be equable in the face of his own demise. It wasn't the first time that he had stiffened himself for a continuation of the fight against his cancer. http://www.irishexaminer.com/opinion/columnists/terry-prone/the-cost-of-hope-and-the-price-to-be-paid-for-refusing-to-accept-death-197735.html

Almost half of unpaid carers risking their health, survey shows

U.K. | *The Guardian* – 18 June 2012 – Nearly half of unpaid carers in the U.K. are jeopardising their health due to a lack of support, according to a survey.¹ Carried out by Carers Week, a group of charities including Age U.K., Carers U.K. and Macmillan Cancer Support, the survey found 40% of carers had put off receiving medical treatment because of the pressures of their role. In addition, 87% of the 3,400 carers surveyed said caring had been detrimental to their mental health, while 83% said they had suffered physical health problems; 36% said they had sustained injuries such as back pain and insomnia while caring for sick or disabled friends or family. A [recent] survey by the Association of Directors of Adult Social Services² revealed social care budgets had been cut by £1.89billion in the last two years, and suffered a drop of 6% last year at a time when pressure from rising numbers of older and disabled adults continues to grow at around 3% each year. http://www.guardian.co.uk/society/2012/jun/18/half-unpaid-carers-risking-health

- 1. 'In Sickness and in health: A survey of 3,400 U.K. carers about their health and well-being,' Carers Week, June 2012. <u>http://carersweek.org/about-carers/insickness-and-in-health</u>
- 'Social care funding cut by £900million last year,' The Guardian, 14 June 2012. <u>http://www.guardian.co.uk/society/2012/j</u> <u>un/14/social-care-funding-cuts</u>

Specialist Publications

Of particular interest:

'Caring for grieving family members: Results from a national hospice survey' (p.11), published in *Medical Care*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | The Guardian 20 June 2012 'Should minimally conscious patients be asked if they
 wish to die?' The ability to communicate with some minimally conscious patients raises ethical
 questions we should think about. <u>http://www.guardian.co.uk/science/neurophilosophy/2012/jun/20/1</u>
- U.K. | Daily Mail 19 June 2012 'My life is miserable, demeaning and undignified says locked-in syndrome sufferer as he asks High Court judges to give him the right to die.' Tony Nicklinson wants ... judges to rule that if, and when, he decides he wants to die, a doctor will be immune from prosecution if they help him. <u>http://www.dailymail.co.uk/news/article-2161494/Tony-Nicklinson-euthanasia-My-life-miserable-undignified-says-locked-syndrome-sufferer.html</u>
- U.K. | Daily Mail 19 June 2012 'Top doctor's chilling claim...' NHS [National Health Service] doctors are prematurely ending the lives of thousands of elderly hospital patients because they are difficult to manage or to free up beds, a senior consultant claimed. Professor Patrick Pullicino said doctors had turned the use of a controversial 'death pathway' into the equivalent of euthanasia of the elderly. <u>http://www.dailymail.co.uk/news/article-2161869/Top-doctors-chilling-claim-The-NHS-kills-130-000-elderly-patients-year.html?ito=feeds-newsxml</u>
- SWITZERLAND | The Local 18 June 2012 'Swiss canton sanctions assisted suicide.' The canton of Vaud has voted in favour of allowing assisted suicide to take place in nursing homes, making it the first formal Swiss law on the subject. http://www.thelocal.ch/3550/20120618/

Media Watch: Editorial Practice

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

Distribution

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

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.

2. Links often remain active, however, for only a limited period of time.

3. Access to a complete article, in some cases, may require a subscription or one-time charge.

4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.

5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

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

Racial differences in hospice use and patterns of care after enrollment in hospice among Medicare beneficiaries with heart failure

AMERICAN HEART JOURNAL, 2012;163(6):987-993. The study population included 219,275 Medicare beneficiaries with heart failure, of whom 31.4% of white patients and 24.3% of nonwhite patients enrolled in hospice in the last 6 months of life. Despite increasing rates of hospice use for both white and nonwhite patients, non-white patients were 20% less likely to enroll in hospice. After enrollment, nonwhite patients were more likely to have an emergency department visit, to be hospitalized, and to have an intensive care unit stay. These differences persisted after adjustment for patient characteristics. Nonwhite patients were also more likely to disenroll from hospice. Among patients who remained in hospice until death, nonwhite patients had higher rates of acute care resource use and higher overall costs. <u>http://www.ahjonline.com/article/S0002-</u> 8703(12)00171-8/abstract

From Media Watch, 4 June 2012:

 JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED, 2012;23(1):28-58. 'What influences African American end-of-life preferences?' http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal of health care for the po or_and_underserved/v023/23.1.wicher.html

From Media Watch, 7 May 2012:

 HOWARD JOURNAL OF COMMUNICATION | Online article – 27 April 2012 – 'African Americans and decisions about hospice care: Implications for health message design.' <u>http://www.tandfonline.com/doi/abs/10.1080/10646175.2012.667724</u>

Palliative care in Germany

Palliative care oriented therapy for all patients: Recommendations of an expert circle

DER ANAESTHESIST, 2012;61(6):529-536. Since 2011 palliative care has been a compulsory part of the German medical study course (so-called Q13 palliative and pain medicine). Palliative care content does not, however, as often taught, have to focus only on patients in the so-called palliative stages of disease. The aim of this investigation was to encourage a discussion concerning the integration of palliative care aspects into general medical treatment. Palliative care treatment is increasingly becoming integrated into medical education and into medical curricula of all disciplines. Palliative ideas and goals are focussed on patients in the so-called palliative stages of disease. As a result of this study it seems to make sense to extend palliative care aspects to all patients and to all patient care. http://rd.springer.com/article/10.1007/s00101-012-2025-1

N.B. Germany was rated 8th (of the 40 countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. <u>http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf</u>



Six understandings of the word 'spirituality' in a secular country

ARCHIVE FOR THE PSYCHOLOGY OF RELIGION, 2012;34(1):63-81. Spirituality is a growing research theme, especially in relation to health issues. The term is often poorly defined and one's understanding is often so broad that it becomes a mere frame word devoid of meaning. In this study, the authors asked 514 adult Danes about their understanding of the word 'spirituality.' Factor analysis of the answers resulted in six different understandings of spirituality: 1) positive dimensions in human life and well-being; 2) New Age ideology; 3) an integrated part of established religious life; 4) a vague striving, opposed to religion; 5) selfishness; and, 6) ordinary inspiration in human activities. It is concluded that a common understanding of the term spirituality does not exist, at least in a modern secular setting. Suggestion for future research is that the term spirituality is not used without an indication, notions or keywords of what is meant by the term in a specific context. http://www.ingentaconnect.com/content/brill/arp/2012/0000034/00000001/art00005

N.B. This issue of the *Archive for the Psychology of Religion* focuses on spirituality. Journal contents page: <u>http://booksandjournals.brillonline.com/content/15736121</u>. See Media Watch, 28 May 2012 (p.7) for a listing of articles, reports, etc., on spirituality in the context of end-of-life care.

Palliative care in Asia

Evaluation of community palliative care settings: A discussion of the issues

ASIA PACIFIC JOURNAL OF HEALTH MANAGEMENT, 2012;7(1):43-48. This article highlights issues about processes and systems of the evaluation itself, rather than the quality of the palliative care provided. Key issues were: project design; achieving an ethical evaluation process; working with vulnerable populations; staff/manager perceptions of evaluation processes; and factors pertinent to funding bodies. Findings are discussed in the light of current literature and strategies for more effective evaluation processes which are appropriate for a very vulnerable population; as well as considering the needs of staff in remote and often staff-poor services, and managers who have responsibilities for healthcare services in which palliative care provision is but a small part. <u>http://search.informit.com.au/documentSummary;dn=409430519661439;res=IELHEA</u>

Timing is everything: When to consult palliative care

JOURNAL OF THE AMERICAN ACADEMY OF NURSE PRACTITIONERS | Online article – 15 June 2012 – Consults promote additional perspectives and help with complex patient management. As the population ages and healthcare demands increase, providers are consulting palliative care (PC). Nurse practitioners (NPs) should understand when to consult PC. Based on the 2009 Clinical Practice Guidelines for Quality PC...¹ The goals of PC are to alleviate suffering and promote quality of life for people with illnesses. <u>http://onlinelibrary.wiley.com/doi/10.1111/j.1745-7599.2012.00746.x/abstract;jsessionid=5EDD088CCE385E7275F8906E7E0C8F81.d01t01?deni edAccessCustomisedMessage=&userIsAuthenticated=false</u>

1. 'Clinical Practice Guidelines for Quality Palliative Care,' National Consensus Project for Quality Palliative Care, 2009. <u>http://www.nationalconsensusproject.org/guideline.pdf</u>

Of related interest:

 BC MEDICAL JOURNAL, 2012;54(6):280. 'Researching 'a good death.'' Medical publishers are rushing to fill the need for information on all aspects of palliative and hospice care, and the Library of the College of Physicians & Surgeons of British Columbia has developed a multimedia collection for registrants to use. <u>http://www.bcmj.org/college-library/researching-%E2%80%9C-gooddeath%E2%80%9D</u>

Hiring and screening practices of agencies supplying paid caregivers to older adults

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online article – 21 June 2012 – To recruit caregivers, agencies primarily used print and Internet advertising and word-of-mouth referrals. In hiring, agencies required prior "life experiences" few of which were specific to caregiving. Screening measures included federal criminal background checks and drug testing. Agencies stated that the paid caregiver could perform skills, such as medication reminding. Skill competency was assessed according to caregiver self-report, testing, and client feedback. General caregiver training length ranged from 0 to 7 days. Supervision ranged from none to weekly and included home visits, telephone calls, and caregivers visiting the central office. Using an agency to hire paid caregivers may give older adults and their families a false sense of security regarding the background and skill set of the caregiver. http://onlinelibrary.wiley.com/doi/10.1111/j.1532-5415.2012.04047.x/abstract

Challenges of do-not-attempt-resuscitation orders

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2012;307(23):2487-2489. Blinderman and colleagues highlighted the challenges faced when considering do-not-attempt-resuscitation decisions.¹ Their recommendations have a number of similarities with the approach currently used in the U.K. Guidance on this topic comes from a joint statement² ... produced by the British Medical Association, the Resuscitation Council (U.K.), and the Royal College of Nursing, and from the General Medical Council's publication.³ These guidelines identify three situations during which cardiopulmonary resuscitation (CPR) may be withheld: 1) when clinical judgment concludes that CPR will not be successful in restarting the patient's heart and breathing and restoring circulation; 2) when, following careful discussion with the patient (and/or those close to him/her), agreement is reached that benefits of CPR are outweighed by the burdens and risks; and, 3) when a patient has an advanced decision (i.e., living will) or makes an informed decision to refuse CPR. http://jama.jamanetwork.com/article.aspx?articleid=1187921

- 'Time to revise the approach to determining cardiopulmonary resuscitation status,' *Journal of the American Medical Association*, 2012;207(9):917-918 (noted in Media Watch, 12 March 2012). <u>http://jama.ama-assn.org/content/307/9/917.extract</u>
- 'Decisions Relating to Cardiopulmonary Resuscitation,' British Medical Association, Resuscitation Council (U.K.), Royal College of Nursing. Decisions Relating to Cardiopulmonary Resuscitation, 2007. <u>http://www.resus.org.uk/pages/dnar.pdf</u>
- 'Treatment and Care Towards the End of Life: Good Practice in Decision Making,' General Medical Council, 2010 (noted in Media Watch, 28 June 2010). <u>http://www.gmc-uk.org/static/documents/content/End_of_life.pdf</u>.

Further comment on Blinderman et al article: Blinderman [et al] discussed a default position of not performing CPR for imminently dying patients in U.S. hospitals unless consent to opt-out is obtained. Similarly, a physician may deem CPR futile and may wish to enter a do-not-attempt-resuscitation order over the objections of the patient or family. Although it may be ethically and medically justified in certain situations, the bulk of case law and statutory interpretation does not support the use of such a ... policy. http://jama.jamanetwork.com/article.aspx?art icleid=1187922

Blinderman et al response: We agree with the assessment that guidelines and regula-

tory processes alone cannot ensure that patients at the end of life are not harmed by CPR and that a focus on communication training is necessary. Our differentiated approach to determining CPR status is not meant to solve the problem of inadequate communication but to create a rational framework for these conversations. Improved communication skills together with guidelines and policies that support the decision to not offer CPR when it is believed to be medically inappropriate or harmful, in our opinion, will be more likely to prevent the harms associated with CPR for terminally ill or dying patients than any single approach by itself. http://iama.iamanetwork.com/article.aspx?art icleid=1187923

Cont.

Of related interest:

 AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY, 2012;20(4):306-316. 'Undetected cognitive impairment and decision-making capacity in patients receiving hospice care.' In general, [study] participants were mildly impaired on measures of verbal learning, verbal memory, and verbal fluency; 54% was classified as having significant, previously undetected cognitive impairment. http://journals.lww.com/ajgponline/pages/results.aspx?k=CZ%20Burton&Scope=AllIssues&txtKeyw ords=CZ%20Burton

Consensus building in palliative care: A Europe-wide Delphi study on common understandings and conceptual differences

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 18 June 2012 – Respondents represented 80% of the member associations of the European Association for Palliative Care, comprising 96 experts and 35 national hospice and palliative care associations from 22 countries. High to very high consensus was found for common values and principles of palliative care (e.g., autonomy, dignity) and the provision of different levels of palliative care. Lower consensus emerged for concepts such as end-of-life care or terminal care, the demand of services and the composition of palliative care teams. The role of social workers was emphasized, but there was ambiguity about the contribution of psychologists. The need for health professionals without specialist palliative care skills to strengthen their contribution to palliative care provision was emphasized. <u>http://www.jpsmjournal.com/article/S0885-3924(12)00145-5/abstract</u>

Development and implementation of a pediatric palliative care program

JOURNAL OF PEDIATRIC NURSING, 2012;27(4):394-401. Research indicates that palliative care reduces length of stay and use of aggressive end-of-life interventions, improves quality of life, and provides hope. It balances provision of coordinated care with building of family memories and preparation for the child's death with celebration of the child's life. The authors advocate implementation of pediatric palliative care in any hospital that cares for children. This article provides a model outlining critical steps and considerations for establishing a successful pediatric palliative care program. http://www.pediatricnursing.org/article/S0882-5963(11)00333-2/abstract

 JOURNAL OF PEDIATRIC NURSING, 2012;27(4):350-356. 'Pediatric palliative care: A conceptual analysis for pediatric nursing practice.' <u>http://www.pediatricnursing.org/article/S0882-5963(11)00280-6/abstract</u>

Hospice in America

Caring for grieving family members: Results from a national hospice survey

MEDICAL CARE, 2012;50(7):578-584. Most hospices [in the U.S.] provided bereavement services to the family (78%) and to the community (76%), but only a minority of hospices provided labor-intensive (23%) or comprehensive (27%) services to grieving family members. The authors report no significant difference in provision of bereavement services to the family, labor-intensive services, or comprehensive services by ownership type; however, non-profit hospices were more likely than for-profit hospices to provide bereavement services to the community. Their results show substantial diversity in the scope and intensity of services provided to families of patients with terminal illnesses, suggesting a need for clearer guidance on what hospices should provide to exemplify best practices. http://www.ncbi.nlm.nih.gov/pubmed/22310561

Of related interest:

 JOURNAL OF PASTORAL CARE & COUNSELING, 2012;66(2). "I want to find my life again": Dementia and grief.' This article challenges spiritual health providers to think beyond the neurologically dissipative symptoms of dementia towards reconstructing clients' identities using new feelings and conceptualizations and drawing from memory-based narratives where possible. http://journals.sfu.ca/jpcp/index.php/jpcp/article/view/443

Evaluation of a novel individualised communication-skills training intervention to improve doctors' confidence and skills in end-of-life communication

PALLIATIVE MEDICINE | Online article – 18 June 2012 – The authors developed a novel individualised training program regarding end-of-life communication, designed to be time effective for busy junior-doctors working in hospital settings. The content of the training intervention was informed by a systematic literature review and evidence-based clinical practice guidelines regarding end-of-life communication. The intervention was based on sound educational principles and involved three one-hour teaching sessions over a three-week period, including two individual sessions with an expert facilitator and simulated patient/caregiver. In addition, participants received written and audiovisual take-home learning materials. All participants reported that the training was useful, had been helpful for their communication with patients and that they would recommend the training to others. Significant improvements were found in participants' communication skills, confidence in communicating about relevant topics, attitudes towards psychosocial care and sense of personal accomplishment. There were no overall differences in participants' burnout levels. http://pmj.sagepub.com/content/early/2012/06/18/0269216312449683.abstract

Economic analysis of potentially avoidable hospital admissions in patients with palliative care needs

PROGRESS IN PALLIATIVE CARE | Online article – 21 June 2012 – In the two hospitals surveyed, the authors' study suggested that 7% of patients with palliative care needs could have been cared for elsewhere. The estimated cost saving of avoiding these admissions and supporting these patients in the community was £1,527 for both hospitals over the survey period. This extrapolates to savings of around £180,000 per annum. Further research is required to gain a better understanding of the economic consequences of potentially avoidable hospital admissions and the extent of variations between localities and to clarify disparities in identified costs. http://www.ingentaconnect.com/content/maney/ppc/pre-prints/1743291X12Y.0000000018

From Media Watch, 11 June 2012:

 AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online article – 23 May 2012 – Why do palliative care patients present to the emergency department? Avoidable or unavoidable?' <u>http://ajh.sagepub.com/content/early/2012/05/18/1049909112447285.abstract</u>

The Ontario psychosocial oncology framework: A quality improvement tool

PSYCHO-ONCOLOGY | Online article – 8 June 2012 – The Psychosocial Health Care for Cancer Patients & Their Families: A Framework to Guide Practice in Ontario and Guideline Recommendations¹ is intended to improve the quality of comprehensive cancer care at both the provider and system levels. <u>http://onlinelibrary.wiley.com/doi/10.1002/pon.3116/abstract</u>

1. 'Psychosocial Health Care for Cancer Patients & Their Families,' Cancer Care Ontario, October 2010. <u>https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=83597</u>

Assisted (or facilitated) death

Representative sample of recent articles, etc:

BMC PUBLIC HEALTH | Online article – 18 June 2012 – 'Age-based disparities in end-of-life decisions in Belgium: a population-based death certificate survey.' This study investigates age-related disparities in the rate of end-of-life decisions with a possible or certain life shortening effect and in the preceding decision making process in Flanders, Belgium in 2007, where euthanasia was legalised in 2002. Comparing with data from an identical survey in 1998 we also study the plausibility of the 'slippery slope' hypothesis which predicts a rise in the rate of administration of life ending drugs without patient request, especially among elderly patients, in countries where euthanasia is legal. http://www.biomedcentral.com/content/pdf/1471-2458-12-447.pdf

Worth Repeating

Redefining the "planning" in advance care planning

ANNALS OF INTERNAL MEDICINE, 2010;153(4):256-261. The traditional objective of advance care planning has been to have patients make treatment decisions in advance of serious illness so that clinicians can attempt to provide care consistent with their goals. Advance directives and documentation of values are the methods most often used to achieve this objective. Although advance directives have shown benefit in some cases, they frequently do not affect the quality of end-of-life care or improve clinician and surrogate knowledge of patient preferences. Substantial improvements have been made in advance directives and advance care planning, but many of these efforts still aim at, and are judged to be successful by, achieving the traditional objective of making advance decisions – an objective that is fundamentally flawed. http://annals.org/article.aspx?volume=153&issue=4&page=25

In-the-moment medical decisions

The authors describe the problems with this traditional objective, provide an alternative objective that focuses on preparing patients and surrogates to make the best possible in-the-moment medical decisions, and outline practical steps that clinicians can take to achieve this new objective in the outpatient setting.

Media Watch Online

Canada

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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

U.S.A.

Prison Terminal: http://www.prisonterminal.com/news%20media%20watch.html

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: <u>http://www.omega.uk.net/news.htm</u> (Scroll down to 'International End of Life Roundup')

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <u>http://centres.sg/</u> (Scroll down to 'What's New: Reading List Update')

International

Australasian Palliative International Link: http://www1.petermac.org/apli/links.htm (Scroll down to 'Media Watch')

Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php

Barry R. Ashpole Beamsville, Ontario CANADA

'phone: 905.563.0044 e-mail: <u>barryashpole@bellnet.ca</u>