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-oflife 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, 2014 ©

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Young people living longer with a terminal illness: Scroll down to <u>Specialist Publications</u> and 'Palliative care answers the challenges of transitioning serious illness of childhood to adult medicine' (p.12), in *Journal of Palliative Medicine*.

<u>Canada</u>

Hassan Rasouli to move out of Sunnybrook after long end-of-life court battle

ONTARIO | The Toronto Star - 31 December 2013 - A patient at the centre of a controversial Supreme Court decision on endof-life care is on a waiting list to be transferred out of hospital to another health-care facility, where he will be expected to pay part of the tab. The move is both good and bad news for Hassan Rasouli and his family. When he is transferred out of Sunnybrook Health Sciences Centre, he will no longer be under the care of doctors who had wanted to remove him from life support. But when he becomes a resident of Toronto's West Park Healthcare Centre, he will have to pay a monthly basic accommodation fee of \$1,707, an amount his family says they cannot afford. Rasouli, 61, has been a critical care patient at Sunnybrook for more than three years. He contracted bacterial meningitis following surgery to remove a benign brain tumour and is now in a minimally conscious state. He is on mechanical ventilation and fed through a feeding tube. His doctors had wanted to remove him from the ventilator, arguing there is no hope of recovery and that he will ultimately die from complications

related to life-support interventions. But his family, who are Shia Muslims, oppose the move for religious reasons. They also argue that he responds to stimulation and has some ability to communicate. The case went all the way to the Supreme Court of Canada, which ruled in October [2013] that the doctors could not unilaterally stop life support. They would first have to obtain consent from Rasouli's family, or, failing that, get permission from Ontario's Consent & Capacity Board, a quasi-judicial body that has legislative authority to rule on such matters. http://www.thestar.com/life/health_wellness/ 2013/12/31/hassan rasouli to move out of sunnybrook after long endoflife court bat tle.html

Specialist Publications

'Technology at the end of life: "Medical futility" and the Muslim persistent vegetative state patient' (p.9), in *International Review of Law.*

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

D.C. program reflects national trend toward moving older Americans out of nursing homes

WASHINGTON STATE | *The Washington Post* – 2 January 2014 – Those who qualify for Medicaid can receive Medicaid-funded services at home; for those who don't, the Office on Aging helps find other funding for in-home care. The office also offers non-medical help such as transportation, meals, and homemaker services to all District residents 60 and older, regardless of income, in accordance with the federal Older Americans Act. The program reflects a trend nationwide toward providing older and disabled people with in-home care rather than keeping them in nursing homes. To encourage this shift, the 2010 Affordable Care Act makes Medicaid benefits more broadly available to people living at home and increases federal funding to states that make more home care services available to those who would otherwise be in nursing homes. So far, 17 states ... have been approved for additional funding. <u>http://www.washingtonpost.com/local/dcprogram-reflects-national-trend-toward-moving-older-americans-out-of-nursinghomes/2014/01/02/8ac1a624-69c7-11e3-ae56-22de072140a2_story.html</u>

A 2014 hospice ad blitz launches amid Obamacare rollout

FORBES | Online – 1 January 2014 – In an effort to improve awareness about hospice and palliative care, the industry is launching a first-ever national education and marketing campaign... The year-long blitz by the National Hospice & Palliative Care Organization, which organizers say will be a "multimillion-dollar" effort, will start ... with a grassroots campaign to get stories from hospice patients and their families. Such stories will then become part of a multi-media campaign to educate Americans about hospice and palliative care and spur a "national conversation on the value of hospice and palliative care." The hospice industry has a financial stake in the campaign's success, particularly as more Americans get medical care coverage this year under the Affordable Care Act and a population of baby boomers ages. More and more medical care providers are incorporating end-of-life care into accountable care organizations, which are contracting with Medicare, Medicaid and private insurers to achieve better outcomes. http://www.forbes.com/sites/brucejapsen/20 14/01/01/amid-obamacare-rollout-hospiceproviders-launch-2014-education-campaign/

Specialist Publications

'The policy debate: Catholic Health Association resources solidly support palliative care' (p.8), in *Health Progress*.

Noted in Media Watch, 30 December 2013, #338 (p.2):

CALIFORNIA | The Washington Post – 26 December 2013 – 'Hospice firms draining billions from Medicare.' 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, an investigation by The Washington Post has found. ttp://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

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

Living wills made clearer in New Hampshire law

NEW HAMPSHIRE | The Associated Press – 30 December 2013 – A dying person's last wishes for what lengths they want doctors to go to keep them alive will be better spelled out after a New Hampshire law takes effect with the New Year. State Senator Peggy Gilmour, the new law's prime sponsor, said the current living will form has caused confusion because it requires people to fill out both a section stating whether they want life-sustaining treatment as well as a separate section on whether they want artificially administered nutrition and hydration. Under the new law, hydration and nutrition are included in the definition of life-sustaining treatment... With the old form, people may have thought they stated that they did not want heroic measures including respirators and feeding tubes, she said. http://www.vnews.com/news/state/region/9992068-95/living-wills-made-clearer-in-nh-law

Of related interest:

CALIFORNIA | The Los Angeles Times (OpEd) – 30 December 2013 – 'No one wants to talk about death, but you need to anyway.' In a culture in which speaking about death and dying has long been taboo, and with a healthcare system that does not foster such conversations, it should come as no surprise that only about 30% of Americans have advance directives for healthcare on file. Even then, an advance directive is just a paper form, and often one that is not accessible at the point of care. http://www.latimes.com/opinion/commentary/la-oe-stulberg-advance-healthcare-planning-20131230,0,5263335.story#axzz2p3iyGGLF

International

"Hospice in a hospital" model in Grantham will be first of its kind in the U.K., says trust

U.K. (ENGLAND) | The Grantham Journal -4 January 2014 – St. Barnabas Hospice has joined forces with the local NHS [National Health Service (Trust)], including GPs, to create a six-bed inpatient unit at Grantham Hospital, which United Lincolnshire Hospitals says is the first venture of its kind in the country. St. Barnabas has invested £1.2 million following a successful bid by the hospice to the Department of Health for £510,000 to help it bring the plans to fruition. The hospice will benefit 160 people every year by having state-of-the-art facilities and specialised end-of-life care on their doorstep. http://www.granthamjournal.co.uk/news/local /hospice-in-a-hospital-model-in-granthamwill-be-first-of-its-kind-in-the-uk-says-trust-1-5784206

Specialist Publications

'Training the powerful: Issues that emerged during the evaluation of a communication skills training programme for senior cancer care professionals' (p.6), in *European Journal of Cancer Care*.

'Barriers to the provision of high-quality palliative care for people with dementia in England: A qualitative study of professionals' experiences' (p.9), in *Health & Social Care in the Community*.

'Palliative care personnel and services: A national survey in Thailand 2012' (p.10), in *Journal of Palliative Care.*

'Palliative care service use in four European countries: A cross-national retrospective study via representative networks of general practitioners' (p.13), in *Plos One.*

Updated 6 January 2014

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.15.

Australia's eHealth record system

End-of-life care wishes clarified

AUSTRALIA (TASMANIA) | *The Examiner* (Launceston) – 2 January 2014 – University of Tasmania professor of nursing Isabelle Ellis said she hoped an electronic advance care planning model ... would see doctors and patients broach the subject of death earlier. Professor Ellis said the model would form part of the Australian Government's personally controlled eHealth record system after trials were finished early this year. She said they had interviewed policy makers, clinicians, nurses, support organisations and older people to identify what they thought should be included in an electronic plan for end-of-life care, who it should be shared with and how it should be accessed. <u>http://www.examiner.com.au/story/2002852/end-of-life-care-wishes-clarified/?cs=95</u>

Some with Alzheimer's find care in far-off nations

U.S. | The Washington Post – 29 December 2013 - Relatives in Western nations are increasingly confronting [Susanna] Kuratli's dilemma as the number of Alzheimer's patients and costs rise, and the supply of qualified nurses and facilities struggles to keep up. Faraway countries are offering cheaper, and to some minds better, care for those suffering from the irreversible loss of memory. The nascent trend is unnerving to some experts who say uprooting people with Alzheimer's will add to their sense of displacement and anxiety, though others say quality of care is more important than location. There's also some general uneasiness over the idea of sending ailing elderly people abroad: the German press has branded it "gerontological colonialism." Germany is already sending several thousand sufferers, as well as the aged and otherwise ill, to

Eastern Europe, Spain and Greece. The Philippines is offering Americans care for \$1,500 to \$3,500 a month, well below U.S. rates. <u>http://www.washingtonpost.com/world/asia_pacific/some-with-alzheimers-find-care-in-far-off-nations/2013/12/30/0e654964-7110-11e3-bc6b-712d770c3715_story.html</u>

Dementia cases "set to treble worldwide" by 2050

U.K. | BBC News – 4 December 2013 – Alzheimer's Disease International says 44 million people presently live with the disease, but that figure will increase to 135 million by 2050. [Noted in Media Watch, 9 December 2013, #335 (p.9)] http://www.bbc.co.uk/news/health-25213162

Noted in Media Watch, 31 December 2012, #286 (p.4):

GERMANY | The Guardian (U.K.) – 26 December 2012 –'Germany "exporting" old and sick to foreign care homes.' Germany's chronic care crisis – the care industry suffers from lack of workers and soaring costs – has for years been mitigated by eastern Europeans migrating to Germany in growing numbers to care for the country's elderly. But the transfer of old people to eastern Europe is being seen as a new and desperate departure, indicating that even with imported, cheaper workers, the system is unworkable. Germany has one of the fastest-ageing populations in the world, and the movement here has implications for other western countries... http://www.guardian.co.uk/world/2012/dec/26/german-elderly-foreign-care-homes

Assisted (or facilitated) death

Representative sample of recent news media coverage:

CHINA | China Radio International (Beijing) – 31 December 2013 – 'Most Chinese have open mind toward euthanasia.' A recent survey shows that more than two-thirds of Chinese have an open and tolerant attitude toward euthanasia, which has long been debated – and banned – in the country. According to the survey ... about 70% of the more than 3,400 polled residents from 34 cities said they do not object to euthanasia or can accept the idea. http://english.cri.cn/6909/2013/12/31/189s805836.htm

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

End-of-life conversations and care: An asset-based model for community engagement

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 January 2014 – Public awareness work regarding palliative and end-of-life care is increasingly promoted within national strategies for palliative care. Different approaches to undertaking this work are being used, often based upon broader educational principles, but little is known about how to undertake such initiatives in a way that equally engages both the health and social care sector and the local communities. An asset-based community engagement approach has been developed that facilitates community-led awareness initiatives concerning end-of-life conversations and care by identifying and connecting existing skills and expertise. http://spcare.bmj.com/content/early/2014/01/02/bmjspcare-2013-000516.abstract

Of related interest:

INTERNAL MEDICINE JOURNAL | Online – 24 December 2013 – 'Medical practitioners' knowledge and self-reported practices of substitute decision-making and implementation of advance care plans.' 34% of specialists and 24% of GPs responded [to a survey]; the majority had heard of all advance care plan options. The findings [of this study, however] suggest significant misunderstanding by medical practitioners of terminologies and systems around substitute decision-making for incompetent persons. Further education and standardisation of terminologies and systems across different jurisdictions would assist in addressing these issues. http://onlinelibrary.wiley.com/doi/10.1111/imj.12354/abstract

In anticipation of grief: Using insights from social epidemiology to improve quality of care

CIRCULATION, 2013;128(25):2725-2728. Although the association between bereavement and mortality, sometimes dubbed "the widowhood effect," has long been recognized, it has not been clear how to translate this empirical association into better health for the surviving spouse. As with many findings on social or psychosocial determinants of health, it is easy to dismiss the widowhood effect as unfortunate but inevitable. The article by Shah *et al*¹ ... upends this perspective by providing compelling evidence on modifiable mechanisms that elevate the cardiovascular risk of surviving spouses. This work fits within the social epidemiology translation framework, which notes that evidence on social risk factors for disease can be used to guide interventions to reduce the incidence of disease, to improve diagnoses so that patients receive timely treatment, and to improve disease management. Effective interventions may target the medical system or individuals and the contexts in which they live. <u>http://circ.ahajournals.org/content/128/25/2725.full</u>

1. 'Impact of partner bereavement on quality of cardiovascular disease management,' *Circulation*, 2013;128(25):2745-2753. <u>http://circ.ahajournals.org/content/128/25/2745.abstract</u>

Of related interest:

- SOCIAL WORK | Online 30 December 2013 'Group work with bereaved individuals: The power of mutual aid.' The use of group work with bereaved individuals is examined... The role and skills of the group worker are identified and illustrated through the use of case examples. Challenges associated with working with groups for bereaved individuals also are discussed. <u>http://sw.oxfordjournals.org/content/early/2013/12/30/sw.swt050.abstract</u>
- SUPPORTIVE CARE IN CANCER | Online 3 January 2014 'Experience of meaning in life in bereaved informal caregivers of palliative care patients.' Meaning in life (MiL) may be a protective factor, but is jeopardised in caregiving and bereavement. This study evaluates the following questions: To what extent do bereaved informal caregivers of palliative care patients experience meaning in their lives? What differences emerge in carers compared to the general German population? How does MiL relate to well-being in former caregivers? http://link.springer.com/article/10.1007/s00520-013-2099-6

Training the powerful: Issues that emerged during the evaluation of a communication skills training programme for senior cancer care professionals

EUROPEAN JOURNAL OF CANCER CARE | Online – 27 December 2013 – 'Connected' is a national advanced communication skills training programme developed in 2008 for cancer care professionals in the National Health Service. A 3-day course combining didactic and experiential learning elements is run by two facilitators with course participants expected to engage fully in simulated consultations with trained actors. In 2011, and as a result of participant feedback on the length of the course and increasing pressures on budgets and clinical time, the 'Connected' team developed and piloted an alternative 2-day training course. Birmingham City University was commissioned to evaluate the effectiveness and quality of the 2-day course *vis-à-vis* the "traditional" 3-day one. This article is written by the two evaluators and it discusses some of the issues that emerged during the evaluation. They broadly grouped these issues into two overlapping categories: 1) the mandatory nature of the course and the different professional background; and, 2) seniority of participants. In their discussion they consider the implications these issues have for communication skills training policy and practice and put forward suggestions for further research. http://onlinelibrary.wiley.com/doi/10.1111/ecc.12167/abstract;jsessionid=34899B9C9B47E0B400 EDAF77DFD4093C.f04t02?deniedAccessCustomisedMessage=&userlsAuthenticated=false

Media Watch: Editorial Practice

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

Distribution

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

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

Why a carefully designed, nurse-led intervention failed to meet expectations: The case of the Care Programme for Palliative Radiotherapy

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online – 21 December 2013 – After a shift from inpatient to outpatient radiotherapy treatment, patients and healthcare professionals perceived shortcomings in the oncological chain of care. The Care Programme for Palliative Radiotherapy was developed in a participative way giving a key role to the nurse practitioners (NP). Evaluation after implementation of the programme showed that patients and professionals were predominantly positive about its effects. However, implementation was not sustained due to lack of institutional and managerial support. The technological innovation far preceded the organisational changes needed to provide innovative, patient-centred care. Implementing this programme with a central role for the NP was seen as the solution to the problems identified. However, in spite of the systematic approach using Participatory Action Research, the programme was not successful in bringing about sustained improvements. More attention should have been paid to the organisational context. http://www.sciencedirect.com/science/article/pii/S1462388913001610

Disclosing the truth: A dilemma between instilling hope and respecting patient autonomy in everyday clinical practice

GLOBAL JOURNAL OF HEALTH SCIENCE, 2014;6(2):128. While medical ethics place a high value on providing truthful information to patients, disclosure practices are far from being the norm in many countries. Transmitting bad news still remains a big problem that health care professionals face in their every day clinical practice. Various electronic databases were searched by the authors and through systematic selection 51 scientific articles were identified. There are many parameters that lead to the concealment of truth. Factors related to doctors, patients and their close environment, still maintain a strong resistance against disclosure of diagnosis and prognosis in terminally ill patients, while cultural influences lead to different approaches in various countries. Withholding the truth is mainly based in the fear of causing despair to patients. However, fostering a spurious hope, hides the danger of its total loss, while it can disturb patient-doctor relationship. http://www.ccsenet.org/journal/index.php/gjhs/article/view/31080

Representative sample of articles on hope and truth-telling in the context of end-of-life care noted in recent issues of Media Watch:

 EUROPEAN JOURNAL OF PALLIATIVE CARE, 2013;20(5):232-236. 'Maintaining hope in emotionally distressed terminally ill patients.' The overwhelming majority of patients [i.e., study [participants] wanted to be told the truth about their prognosis. Most patients also hoped for alleviation of pain and other physical symptoms, support from their family and a reasonable quality of life for as long as possible. [Noted in Media Watch, 16 September 2013, #323 (p.11)]

N.B. Access to the *European Journal of Palliative Care* requires a subscription: <u>http://www.haywardpublishing.co.uk/ejpc.aspx</u>

- NEW ENGLAND JOURNAL OF MEDICINE, 2013;26(368):2448-2450. 'Uncertainty the other side of prognosis.' Prognoses will always have inherent uncertainty, which is often difficult for patients, their families, and even physicians to deal with. But there are ways clinicians can communicate more effectively to help patients and families manage uncertainty. [Noted in Media Watch, 1 July 2013, #312 (p.11)] http://www.nejm.org/doi/full/10.1056/NEJMp1303295
- PALLIATIVE MEDICINE | Online 15 April 2013 'Should palliative care patients' hope be truthful, helpful or valuable? An interpretative synthesis of literature describing health-care professionals' perspectives on hope of palliative care patients.' Three perspectives on hope ... were found: 1) realistic perspective hope as an expectation should be truthful, and healthcare professionals focused on adjusting hope to truth; 2) functional perspective hope as coping mechanism should help patients, and professionals focused on fostering hope; and, 3) narrative perspective hope as meaning should be valuable for patients, and healthcare professionals focused on interpreting it. [Noted in Media Watch, 22 April 2013, #302 (p.12)] http://pmj.sagepub.com/content/early/2013/04/11/0269216313482172.abstract

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

The policy debate: Catholic Health Association resources solidly support palliative care

HEALTH PROGRESS, January-February 2014. The Association's public policy positions long have embraced the importance of providing compassionate care to all people, especially to those facing serious illness – those in pain or those who are dying. In addition to our long tradition, the *Ethical & Religious Directives for Catholic Health Care Services* call on Catholic health care organizations to be communities of respect, love and support for patients and their families as they confront the reality of death.¹ The *Directives* serve to remind us that one of the primary purposes of medicine in caring for the dying is the relief of pain and the suffering caused by it. Unfortunately, in today's health delivery system, patients often confront a complex, fragmented and uncoordinated array of services, which leaves both them and their families of a broken delivery system, patients and their families of a broken delivery system, patients and their families of a broken delivery system, patients and their families of a broken delivery system, patients and their families of a broken delivery system, patients and their families of a broken delivery system, patients and their families often lack the necessary information and support to make informed decisions about their care. All too often, the result is patients receiving care they either don't want or don't need. http://www.chausa.org/publications/health-progress/article/january-february-2014/the-policy-debate-cha-resources-solidly-support-palliative-care

 Ethical & Religious Directives for Catholic Health Care Services, 5th Edition, United States Conference of Catholic Bishops, 17 November 2009. <u>http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf</u>

N.B. This issue of *Health Progress* includes several articles on end-of-life care from a Catholic perspective. Journal contents page: <u>http://www.chausa.org/publications/health-progress</u>

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

Noted in Media Watch, 21 March 2011, #189 (p.9):

THE HASTINGS REPORT, 2011;41(2):28-29. 'Making sense of the Roman Catholic directive to extend life indefinitely.' In November 2009, the U.S. Conference of Catholic Bishops issued Ethical & Religious Directives for Catholic Health Care Services, requiring that all patients ... be provided with artificial hydration and nutrition if such care could extend life indefinitely.¹ http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=5164



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

Barriers to the provision of high-quality palliative care for people with dementia in England: A qualitative study of professionals' experiences

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 27 December 2013 – Approaches to palliative care that were originally developed for people with cancer are now being adopted for people with dementia, as a response to many reports of poor-quality care for people with dementia at the end of life. This study explored perceived barriers to the delivery of high-quality palliative care for people with dementia... Four themes were identified as barriers to providing high-quality palliative care; 2) disconnection between services; 3) different assumptions about training needs; and, 5) negotiation of risk. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12094/abstract

Representative sample of articles on end-of-life care for people living with dementia noted in recent issues of Media Watch:

- DEMENTIA, 2014;13(1):96-110. 'Palliative care services for people with dementia: A synthesis of the literature reporting the views and experiences of professionals and family carers.' What emerges ... 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. [Noted in Media Watch, 30 December 2013, #338 (p.8)] http://dem.sagepub.com/content/13/1/96.abstract
- PALLIATIVE MEDICINE | Online 4 July 2013 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care.' The authors provide the first definition of palliative care in dementia and a framework to provide guidance for clinical practice, policy and research. Sixty-four experts from twenty-three countries evaluated a set of eleven domains and fifty-seven recommendations. [Noted in Media Watch, 8 July 2013, #313 (p.10)] http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract

Technology at the end of life: "Medical futility" and the Muslim persistent vegetative state patient

INTERNATIONAL REVIEW OF LAW | Online - 21 December 2013 - Advanced life-sustaining technologies can now prolong indeterminately the lives of patients in a persistent vegetative state (PVS). However, where the assistance rendered is not expected to restore consciousness, they are considered futile from a medical perspective. English law, in such a scenario, has taken the view it is not in the best interests of the patient to continue to receive medical intervention. This makes it lawful to discontinue all life-sustaining treatment and medical support measures including the termination of clinically assisted nutrition and hydration. The withdrawal of such apparatus, which is classified as medical treatment, is deemed as an omission rather than negligence or an act which causes death. In light of this, the law holds that doctors are merely allowing such patients to die a natural death rather than bringing about their death. The medical debate on the matter, which is underpinned by a series of intertwined medico-legal concepts which justify the English Law position, is often considered as settled. The U.K. Court of Protection was nevertheless recently asked to resolve a conflict between the family of a Muslim PVS patient who objected to his doctors' intention to withhold resuscitation or ventilation should there be a life-threatening event on the grounds that such measures would be futile and thereby not in the patient's best interests. The family instead insisted all steps should be taken to preserve the patient's life until such time that God takes it away. This paper seeks to discuss how such medical futility or at least the semantic conceptual landscape (which also includes best interests, omissions and medical treatment) that determines the legal position is dealt with under Islamic Law with a view to assess its compatibility with English Law. http://www.gscience.com/doi/pdfplus/10.5339/irl.2013.9

Cont.

N.B. The authors cite the case of Hassan Rasouli. News media coverage and commentaries and OpEds in specialist publications in the fields of bioethics and medicine on the issue of withdrawal or withholding of life-sustaining treatment have been noted on a regular basis in Media Watch. Most recent: 21 October 2013, #328 (p.1); 22 July 2013, #315 (pp.2-3,7); 27 May 2013, #307 (p.1); and, 17 December 2012, #284 (p.10). The Canadian Critical Care Society is currently reviewing current guidelines on withholding or withdrawal of life support (noted in Media Watch, 23 December 2013, #337, p.2).

Noted in Media Watch, 28 March 2011, #194 (p.10):

JOURNAL OF MEDICAL ETHICS | Online – 23 March 2011 – 'Disclosure of terminal illness to patients and families: Diversity of governing codes in 14 Islamic countries.' Codes for 14 Islamic countries were located. Five codes were silent regarding informing the patient, seven allowed concealment, one mandated disclosure and one prohibited disclosure. Five were silent regarding informing the family, four allowed disclosure and five mandated/recommended disclosure. The Islamic Organization for Medical Sciences code was silent on both issues. http://jme.bmj.com/content/early/2011/03/22/jme.2010.038497.abstract

N.B. Additional articles on end-of-life care and Islam law are footnoted in this issue of Media Watch.

Of related interest:

 INTERNATIONAL NURSING REVIEW | Online – 30 December 2013 – 'Commitment to care: A qualitative study of intensive care nurses' perspectives of end-of-life care in an Islamic context.' The findings of this study indicate that there is a need for policies that help increase the quality of life of dying patients. It is imperative that nursing managers and policy makers in Iran consider these findings to improve end-of-life care in intensive setting. More training programmes, further education and research on the topic, should be implemented. http://onlinelibrary.wiley.com/doi/10.1111/inr.12079/abstract

Palliative care personnel and services: A national survey in Thailand 2012

JOURNAL OF PALLIATIVE CARE, 2013;29(3):133-139. Research on palliative care services in Thailand is incomplete. The overall response rate of government hospitals was 61% (537 of 882 hospitals). Of these, 59% reported that they had personnel trained in palliative care; the majority had received less than a week of such training. In all, 60% of the hospitals reported that they offered palliative care services, but 25% of these services were delivered by staff who had no palliative care training. The criteria of having at least one trained doctor and nurse on staff was met by 17% of the hospitals. Only seven hospitals, most of them associated with medical schools, employed both a doctor and a nurse who had been trained in palliative care for one month or more; these professionals mainly provided hospital and home palliative care team services. The survey reveals the lack of both health care personnel fully trained in palliative care and specialist palliative care services in Thailand. http://www.ncbi.nlm.nih.gov/pubmed/24380211

Noted in Media Watch, 9 July 2012, #261 (p.7):

SOCIAL SCIENCE & MEDICINE, 2012;75(5):836-844. 'On ethical locations: The good death in Thailand, where ethics sit in places.' In Northern Thailand, many feel that it is ethical to withdraw life support in the home, but unethical to withdraw it in the hospital. This is because the place of death is partly responsible for the quality of rebirth. Hospitals, on one hand, are powerful for saving lives; but as places to die, they are amoral, dangerous, devoid of ceremonial history and haunted by spirits. Homes, on the other hand, are optimal for dying because they are imbued with moral power from a history of beneficial ceremony and family living. http://www.sciencedirect.com/science/article/pii/S0277953612003383

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Noted in Media Watch, 5 September 2011, #217 (p.7):

ASIA | The Times of India – 29 August 2011 – 'Sri Lanka, Thailand to adopt Kerala model in palliative care.' India's Institute of Palliative Medicine [IPM] ... will help developing countries like Sri Lanka, Thailand, Ethiopia and Seashell Island to adopt the Kerala model of a cost-effective community-based palliative care system. In Thailand, the IPM – the only World Health Organisation collaborating centre in the developing countries – will work with Khon Khen University and the National Research University. http://articles.timesofindia.indiatimes.com/2011-08-29/kozhikode/29940820_1_palliative-care-kerala-model-countries

Prevalence and predictors of transition to a palliative care approach among hospital inpatients in England

JOURNAL OF PALLIATIVE CARE, 2013;29(3):147-153. The authors conducted a prospective survey of hospital inpatients in two hospitals in the U.K. in which they examined hospital case notes for evidence of palliative care need. Further data were collected from medical staff, nursing staff, patients, and proxy consultees. Of 514 participating patients, 183 (36.2%) fulfilled criteria for palliative care need. In 61 cases (33%), there was evidence of transition to a palliative care approach. There was an increased likelihood of palliative care transition among patients with cancer, dementia, or stroke. There is a need for discussion of the meaning, and operationalization, of palliative care transitions if U.K. policy to increase the extent of transitions is to be enacted. http://www.ncbi.nlm.nih.gov/pubmed/24380213

Noted in Media Watch, 2 December 2013, #334 (p.11):

HEALTH SERVICES & DELIVERY RESEARCH, 2013;1(11). 'Transitions to palliative care for older people in acute hospitals: A mixed-methods study.' Of the patients in the inpatient survey sample, just over one-third met one or more of the [U.K.] Gold Standards Framework (GSF) prognostic indicator criteria for palliative care needs. The most common GSF prognostic indicator was frailty, with almost one-third of patients (27%) meeting this criteria. Agreement between medical and nursing staff and the GSF with respect to identifying patients with palliative care needs was poor. http://www.journalslibrary.nihr.ac.uk/hsdr/volume-1/issue-11

The size, share, and predictors of publicly financed healthcare costs in the home setting over the palliative care trajectory: A prospective study

JOURNAL OF PALLIATIVE CARE, 2013;29(3):154-162. The increasing attention on home-based service provision for end-of-life care has resulted in greater financial demands being placed on family caregivers. The purpose of this study was to assess publicly financed costs within a home-based setting from a societal perspective. While publicly financed costs accounted for 20% of the full economic costs and increased with proximity to death, 76.7% of costs were borne by patients' caregivers in the form of unpaid caregiving. The share of publicly financed healthcare costs was driven by patients' and caregivers' socio-demographic and clinical characteristics. These findings warrant affording greater attention to policies and interventions intended to reduce the economic burden on palliative patients and their caregivers. <u>http://www.ncbi.nlm.nih.gov/pubmed/24380214</u>

Of related interest:

 JOURNAL OF CLINICAL NURSING | Online – 26 December 2013 – 'Maintaining ordinariness around food: Partners' experiences of everyday life with a dying person.' When a dying person receives care at home, eating deficiencies can influence everyday life for family members, who often take responsibility for the provision of food and meals. The literature reveals this to be emotionally stressful. The partners [i.e., study participants] described experiences of how eating deficiencies brought about changes in the participants' everyday lives. http://onlinelibrary.wiley.com/doi/10.1111/jocn.12518/abstract;jsessionid=E4E8D90FCF5B511
 B7D85E62F7E11F24B.f04t03?deniedAccessCustomisedMessage=&userlsAuthenticated=fals

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 JOURNAL OF PALLIATIVE CARE, 2013;29(3):170-177. "What she told us made the world of difference": Carers' perspectives on a hospice at home service.' A hospice at home service was established in 2006... The authors examined whether this model of care was helpful in mitigating carers' burden and in enabling terminally ill patients to be cared for and die at home. Carers' expectations of the service were often exceeded, and quality of care dimensions were rated highly. Improvements could include facilitating discussions on place of death and offering bereavement support. http://www.ncbi.nlm.nih.gov/pubmed/24380216

Palliative care answers the challenges of transitioning serious illness of childhood to adult medicine

JOURNAL OF PALLIATIVE MEDICINE | Online – 31 December 2013 – Advances in the field of medicine have improved the overall life expectancy in children. Consequently, many children with previously lethal diseases now live into adulthood. There is an urgent need to develop approaches that assist with the transition of care from pediatrics to adult medicine. Palliative care, by virtue of its unique skills, is ideally positioned to play a part in this transition. This report will summarize the urgency for proper transition modalities and then introduce palliative care as a proposed solution for current challenges in transition. Along the way, it will touch on financial and workforce obstacles to this solution and will offer a potential funding option. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0263

Representative sample of articles on the transition to adult services for young people living with a terminal illness noted in recent issues of Media Watch:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 6 November 2013

 'Young adult palliative care: Challenges and opportunities.' From the data, two primary themes emerged 1) ongoing young adult development not only generates unique biologic disease burdens and clinical treatment options, but also requires frequent assessment and promotion; and, 2) binary health care systems often leave young adults without access to developmentally appropriate health care. [Noted in Media Watch, 11 November 2013, #331 (p.6)] http://ajh.sagepub.com/content/early/2013/11/06/1049909113510394.abstract
- PALLIATIVE MEDICINE | Online 18 October 2013 'Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study.' Transition to adult services and adulthood is a prospect for young people with life-limiting conditions requiring palliative care. Transition planning [among the study participants] was absent or poorly coordinated; for most families, there were no equivalent adult health/social services. [Noted in Media Watch, 21 October 2013, #328 (p.13)] http://pmj.sagepub.com/content/early/2013/10/15/0269216313507626.abstract

Of related interest:

- FAMILIES, SYSTEMS, & HEALTH, 2013;31(4):406-413. 'Perspectives of parents on making decisions about the care and treatment of a child with cancer: A review of literature.' Seventeen articles were identified that focused specifically on the decisions parents make regarding the care and treatment of children with cancer. Coders agreed that the child's quality of life/well-being, parental hope/expectations, support/supportive care, communication, and information were important themes in considering the decisions parents made regarding the care and treatment of children with cancer. <u>http://psycnet.apa.org/journals/fsh/31/4/406/</u>
- JOURNAL OF PALLIATIVE CARE, 2013;29(3):186-192. 'The voices of young New Zealanders involved in pediatric palliative care.' Inductive thematic analysis revealed several concerns of [study] participants, including special treatment that patients had received, spending time with their families, their feelings of being judged or discriminated against, their sense of being understood themselves and of understanding others, and mortality. A nonjudgemental, open approach is recommended when consulting with patients and their siblings in order to determine their needs. <u>http://www.ncbi.nlm.nih.gov/pubmed/24380218</u>

Spirituality and uncertainty at the end of life

ONCOLOGY NURSING FORUM, 2014;41(1):33-39. [In this study] spirituality and uncertainty were compared for theoretical congruency based on five general categories: prevalence, temporality, interpretation, quality, and directionality. The categories were drawn from the uncertainty literature and looked at the ability of spirituality and uncertainty to contribute to or detract from health. This article presents an innovative way of viewing how spirituality is experienced at the EOL [end of life]. The likelihood that uncertainty and spirituality can coexist as a simultaneous and even blended construct that influences the EOL is supported and warrants additional exploration. Health professionals must recognize the prevalence of spiritual uncertainty in the lives of their patients and understand the need to frequently assess for spiritual uncertainty. Specific recommendations are provided to guide professionals in addressing spiritual uncertainty with patients. http://ons.metapress.com/content/gu254t23r3126830/

Representative sample of articles on spirituality and end-of-life care noted in recent issues of Media Watch:

ARCHIVE FOR THE PSYCHOLOGY OF RELIGION, 2012;34(1):63-81. 'Six understandings
of the word 'spirituality' in a secular country.' Spirituality ... is often poorly defined and
one's understanding is often so broad that it becomes a mere frame word devoid of meaning. It
is concluded that a common understanding of the term spirituality does not exist, at least in a
modern secular setting. [Noted in Media Watch, 25 June 2012, #259 (p.9)]
http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/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>.

- JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2013;9(2-3):111.
 'Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.' This issue of the journal gives a snapshot of theoretical and practice perspectives in which spirituality plays a key role in end-of-life care.¹ [Noted in Media Watch, 24 June 2013, #311 (p.12)] http://www.tandfonline.com/doi/full/10.1080/15524256.2013.793988
 - 1. Journal contents page: <u>http://www.tandfonline.com/toc/wswe20/current</u>

Palliative care service use in four European countries: A cross-national retrospective study via representative networks of general practitioners

PLOS ONE | Online – 30 December 2013 – Population-based data on the number of people receiving palliative care in Europe are scarce. The objective of this study is to examine, in four European countries, the number of people receiving palliative care in the last three months of life and the factors associated with receiving palliative care. The authors studied 4,466 deaths. GPs perceived to have delivered palliative care to 50% of patients in Belgium, 55% in Italy, 62% in The Netherlands, and 65% in Spain. Palliative care specialists attended to 29% of patients in The Netherlands, 39% in Italy, 45% in Spain, and 47% in Belgium. Cancer patients were more likely than non-cancer patients to receive palliative care in all countries as were younger patients in Italy and Spain. Although palliative care is established in the countries studied, there are considerable differences in its provision. Two potentially underserved groups emerge non-cancer patients in all countries and older people in Italy and Spain. Future research should examine how differences in palliative care use relate to both patient characteristics and existing national health care policies. <u>http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0084440</u> Representative sample of articles on the provision and delivery of hospice and palliative care in Europe noted in recent issues of Media Watch:

- 'Nationwide continuous monitoring of end-of-life care via representative networks of general practitioners in Europe,' *BMC Family Practice*, 3 June 2013. The European Sentinel GP Networks Monitoring End of Life Care (EURO SENTIMELC) study was designed to describe and compare the last months of life of patients dying in different European countries [Belgium, The Netherlands, Italy and Spain]. The authors describe how representative GP networks in the EURO SENTIMELC study operate to monitor end of life care in a country, to describe used methodology, research procedures, representativity and characteristics of the population reached using this methodology. [Noted in Media Watch, 10 June 2013, #309 (p.8)] http://www.biomedcentral.com/content/pdf/1471-2296-14-73.pdf
- Comparison of legislation, regulations and national health strategies for palliative care in seven European countries: A descriptive study,' BMC Health Services Research, 17 July 2013. Access to palliative care was mentioned by all countries, varying from explicit regulations to policy intentions in national plans. All countries had a national policy on palliative care, although sometimes mainly related to national cancer plans. Differences existed in policy regarding palliative care leave, advance directives, national funding, palliative care training, research, opioids and the role of volunteers. [Noted in Media Watch, 29 July 2013, #316 (p.8)] http://www.biomedcentral.com/content/pdf/1472-6963-13-275.pdf
- 'Atlas of palliative are in Europe 2013,' European Association for Palliative Care, 29 May 2013. An aim of this study is to provide governments and policymakers with an understanding of the development of programs to promote palliative care and, in turn, have a positive impact upon providers of palliative care services in a direct, practical way through an improvement in the development of policy and practice and future service design. [Noted in Media Watch, 3 June 2013, #308 (p.10)] http://issuu.com/universidaddenavarra/docs/atlas_europa_full_edition
- 'Learning from the public: Citizens describe the need to improve end-of-life care access, provision and recognition across Europe,' European Journal of Public Health, 13 March 2013. Many European countries lack national policies regarding palliative and end-of-life care. Research revealed two prominent themes: 1) a need for improved quality of end-of-life and palliative care, and access to this care for patients and families; and, 2) the recognition of the importance of death and dying, cessation of treatments to extend life unnecessarily, and the need for holistic care to include comfort and support. [Noted in Media Watch, 18 March 2013, #297 (p.9)] http://eurpub.oxfordjournals.org/content/early/2013/03/13/eurpub.ckt029.abstract
- 'Validation of quality indicators for the organization of palliative care: A modified RAND Delphi study in seven European countries (the Europall project),' Palliative Medicine, 16 July 2013. No international set of quality indicators to measure the organizational aspects of palliative care settings exists. [Noted in Media Watch, 22 July 2013, #315 (p.13)] http://pmj.sagepub.com/content/early/2013/07/15/0269216313493952.abstract

Assisted (or facilitated) death

Representative sample of recent articles, etc:

JOURNAL OF MEDICAL ETHICS | Online – 3 January 2014 – 'Labelling of end-of-life decisions by physicians.' In the vast majority of practices labelled as euthanasia, the self-reported actions of the physicians [i.e., study participants] corresponded with the definition in the Belgian euthanasia legislation; practices labelled as palliative or terminal sedation lack clear correspondence with definitions of sedation as presented in existing guidelines. In these cases, an explicit life-shortening intention by means of drug administration was present in 21.6%; life shortening was estimated at more than 24 hours in 51% and an explicit patient request was absent in 79.7%. The authors' results suggest that, unlike euthanasia, the concept of palliative or terminal sedation covers a broad range of practices in the minds of physicians. http://jme.bmj.com/content/early/2014/01/03/medethics-2013-101854.abstract

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	INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-
	iahpc/newsletter/2013/12/media-watch/
	INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <u>http://www.ipcrc.net/archive-global-palliative-care-news.php</u>
	PALLIATIVE CARE NETWORK COMMUNITY: <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>
	PALLIMED (Hospice & Palliative Medicine Blog): <u>http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html</u> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]
	Asia
	ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <u>HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/</u>
	SINGAPORE Centre for Biomedical Ethics (CENTRES): <u>http://centres.sg/updates/international-palliative-care-resource-</u> center-media-watch/
	Australia
	WESTERN AUSTRALIA Palliative Care WA Inc: <u>http://palliativecarewa.asn.au/site/helpful-resources/</u> [Scroll down to 'International Websites' and <u>www.ipcrc.net/archive-global-palliative-care-news.php</u> to access the weekly report]
	Canada
New	ONTARIO Central Regional Hospice Palliative Care Program: http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1
	ONTARIO Central West Palliative Care Network: <u>http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1</u>
	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: <u>http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1</u>
	ONTARIO Palliative Care Consultation Program (Oakville): <u>http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/</u> [Scroll down to 'Additional Resources']
	ONTARIO Toronto Central Hospice Palliative Care Network: <u>http://www.tcpcn.ca/news-events</u> [Scroll down to 'Media Watch']
	Europe
	EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <u>http://www.eapcnet.eu/Themes/Organization/Links.aspx</u> [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-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c
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