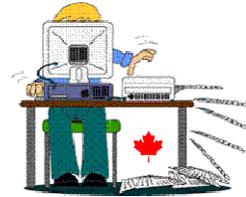


Media Watch...

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.

21 May 2012 Edition | Issue #254



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

Compiled & Annotated by Barry R. Ashpole

The well-being of the patient in body, mind and spirit: Scroll down to [Specialist Publications](#) and 'What can we learn about the spiritual needs of palliative care patients from the research literature?' (p.7), published in the *Journal of Pain & Symptom Management*.

Canada

Hassan Rasouli case

Top court to hear doctors' end-of-life appeal

ONTARIO | CTV News – 17 May 2012 – The Supreme Court of Canada [is] to hear an appeal by doctors over who has the final authority to end a comatose patient's life. The court's ruling on the controversial case involving a Toronto man could clear up a legal grey area that fails to clarify whether physicians or a patient's family have the final say on when to pull the plug. The justices refused to throw out the case, saying it will get a full hearing later this year. Five months after... Hassan Rasouli brought his family to Canada from Iran in 2010, he had routine surgery for a benign brain tumour. Bacterial meningitis infected his brain leaving him unresponsive. Within weeks, the surgeons wanted the family to take Rasouli off a ventilator that was keeping him alive, but his wife, a doctor in her native Iran, thought it was too soon. The story changed in January 2011 when Rasouli's family thought he started showing signs of improvement, even though his diagnosis maintained he was in a persistent vegetative state. In Ontario, cases ... where there is no agreement are supposed to be referred to an expert tribunal ... the Consent & Capacity Board [CCB]. Doctors at

Sunnybrook Hospital refused to do that and instead took the case to the Ontario Superior Court in February 2011 [which] rejected the doctors' arguments that they didn't need consent to remove life support and ruled that Rasouli's case ... be referred to the CCB. The doctors' case was rejected again by the Ontario Court of Appeal in June 2011. It was then appealed to the Supreme Court of Canada. In an interesting twist, Rasouli is now considered to be "responsive" ... That means the court ruling would no longer apply specifically to Rasouli and his ventilator won't be removed regardless of the outcome. <http://winnipeg.ctv.ca/servlet/an/local/CTVNews/20120517/SCOC-appeal-Rasouli-120517/20120517/?hub=WinnipegHome>

Specialist Publications

Of particular interest:

'Withdrawal of life-sustaining treatment from a patient in a minimally conscious state' (p.6), published in the *Journal of Law & Medicine*.

U.S.A.

End of life shouldn't be spent in hospital, expert contends

ARIZONA | *The Republic* – 17 May 2012 – Dying well – pain free, at home, with dignity and loving support – is what most of us want, said Ira Byock, one of the nation's foremost experts on end-of-life care. But even now – 35 years after the modern-day hospice movement began, with 5,000 hospice programs nationwide – it's still not what most of us get. While surveys show most people would prefer to die comfortably at home, about 70% die in institutions, with 20% of those dying in intensive-care units. America has reached a fork in the road about end-of-life care. Either the nation continues escalating the expensive "disease-treatment system" that imposes increasing burdens of illness on people with life-limiting diseases or patients should be given the option to die a natural death at home surrounded by people they love, Byock said. "We Baby Boomers need to get back in our game. We transformed the birth process, making it a personal experience, not a medical event. The same transformation needs to take place at end of life. It's time to take it back." <http://www.azcentral.com/community/mesa/articles/2012/05/15/20120515end-life-shouldnt-spent-hospital-expert-contends-nby.html>

Taking care: What are you waiting for? Benefits of early hospice intervention

FLORIDA | *TC Palm* (Vero Beach) – 14 May 2012 – "I wish we had been referred to Hospice sooner." It's a sentiment that recurs in patient and family surveys returned to hospices each year. Hospice is traditionally thought to be for patients who are in the last six months of life, but some patients receive hospice services for years if their disease process is slow. Because hospice is focused on living, people who utilize hospice services early in the course of a life-limiting illness have more time to develop personal and professional rapport with hospice staff and volunteers, discuss goals, and create an optimal plan of care designed around patient and family wishes. Patients who are referred to hospice care early in their disease process can receive the full benefit of hospice

care, including seeing their medical, social, and spiritual needs met. One of hospice's goals is pain and symptom management and is just one of the benefits of early referral. <http://www.tcpalm.com/news/2012/may/14/taking-care-what-are-you-waiting-for-benefits-of-e/>

Specialist Publications

Of particular interest:

'Evolution of end-of-life care at U.S. hospitals in the new millennium' (p.7), published in the *Journal of Palliative Medicine*.

International

Free home care available to fewer elderly people

U.K. (ENGLAND) | *The Guardian* – 16 May 2012 – The number of vulnerable older and disabled people who had home care services fully paid by their local authority fell by 11% in England in the past two years, according to newly published figures. The data also reveals wide variations in council charges across England. Freedom of information requests to 120 councils revealed that home care services ... are becoming more expensive and inaccessible to many of the population. <http://www.guardian.co.uk/society/2012/may/16/free-home-care-elderly-people>

 World hospice & palliative care day **October 13 2012**
<http://www.worldday.org/>

Dying Matters Coalition survey

People in Britain could risk missing out on having their end of life wishes met

U.K. | ComRes – Accessed 15 May 2012 – Research ... finds that although more than half of Brits (54%) have been bereaved in the last five years and a third think about dying and death weekly and 11% say they think about it daily, discussing dying and making end of life plans remains a taboo for many people, including doctors. More than two-thirds (71%) of the public agree that people in Britain are uncomfortable discussing dying, death and bereavement. This is a view shared by GPs, with 79% saying that people in Britain are uncomfortable discussing dying. Talking about dying, even with family and friends, is also a taboo for many. A quarter (25%) of Brits said they felt uncomfortable discussing dying with those close to them. Only sex is more of a taboo subject than dying, with 39% of Brits reporting feeling uncomfortable discussing sex with family and friends, compared with money (23%), religion (14%) politics (13%) and immigration (11%). Despite this widespread reluctance to talk, most people can see the benefits of more open discussion about dying: 78% of the public and 88% of GPs agree that if Brits felt more comfortable discussing dying, death and bereavement it would be easier to have our end of life wishes met. <http://www.comres.co.uk/poll/669/dying-matters-coalition-survey-of-gps-and-the-public.htm>

Health body urges open discussion about death

U.K. (NORTHERN IRELAND) | *Belfast Telegraph* – 15 May 2012 – Northern Ireland's Public Health Agency [PHA] is urging everyone to make an opportunity to talk openly about dying, death and bereavement with their loved ones. Health Minister Edwin Poots is backing calls for "open and honest discussion"... The PHA says ... that many people have specific wishes about their end-of-life care or what they would like to happen after their death. But there is also a reluctance to discuss these issues, making it much less likely that these will be met. It found that 70% of people would prefer to die at home but more than half currently die in hospital. Mr. Poots said good palliative and

end-of-life care is an important part of health and social care services in Northern Ireland. <http://www.belfasttelegraph.co.uk/news/health/health-body-urges-open-discussion-about-death-16158818.html>

Specialist Publications

Of particular interest:

'Don't dodge the difficult conversation, says new report' (p.5), published in the *British Journal of Cardiology*.

150-bed palliative care centre in Thalambur

INDIA | IBN Live (Chennai)– 14 May 2012 – Touted as the first of its kind in India, a 150-bed palliative care centre is to be inaugurated in the Sri Venkateshwara Dental College Campus in Thalambur. Conceptualised and built by Vel's Charitable Trust, the Shri Isari Velan Mission Hospital is named after founder Dr. Isari K Ganesh's father on the occasion of his 25th death anniversary. <http://ibnlive.in.com/news/150bed-palliative-care-centre-in-thalambur/257342-60-120.html>

N.B. India was rated 40th (of forty countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

How do you talk to children about death?

U.K. | BBC 4 ('Today') – 14 May 2012 – More than two-thirds of the public admit they are uncomfortable discussing the issue of dying, according to a poll by Dying Matters, an umbrella group of charities, care homes and hospices led by the National Council for Palliative Care. Rabbi Julia Neuberger suggested ... that not discussing death from a young age is contributing to this discomfort and that death education should be broached in school. Shelley Gilbert, founder of Grief Encounter, a charity that deals with child bereavement, told the Today programme that adults and teachers should "safely encourage" conversations about death, but warned that "we need to educate the educators" in order to deal with the

questions responsibly. Children's author Judith Kerr deals with death in some of her books, but says she does not believe the classroom is the right place for discussion. http://news.bbc.co.uk/today/hi/today/newsid_9720000/9720673.stm

Specialist Publications

Of particular interest:

'National survey of children's hospitals on legacy-making activities' (p.7), published in the *Journal of Palliative Medicine*.

Senate inquiry

I'm right to go, just don't wake me

AUSTRALIA (VICTORIA) | *Wyndham Weekly* – 11 May 2012 – Some people tattoo "do not resuscitate" on their chests to ensure a say over their way of dying. The Minister for Ageing, Mark Butler, says he has witnessed a man in Newcastle rip off his shirt to expose the message. A woman he met in Darwin boasted a similarly placed tattoo, and on her back the letters "PTO" – please turn over. Mr. Butler came across the tattooed advocates during his recent marathon "conversation" tour around Australia to consult on aged care. "Having control over the circumstances of your own death was raised at every conversation," he told the *Herald*. "What I heard time and time again is that older Australians want to be reassured that they will be able to choose where they die and the circumstances of their death. They want to die in their own homes and not in hospitals, where 70% of people currently die." Australia's confused approach to advanced care directives over end-of-life decisions is being explored by a Senate committee inquiry into palliative care. And for the first time the federal government is funding palliative care advisory services. <http://www.wyndhamweekly.com.au/news/national/general/im-right-to-go-just-dont-wake-me/2552537.aspx>

N.B. Australia was rated 2nd (of forty countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010.

http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

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

Burden and needs of 487 caregivers of patients in vegetative state and in minimally conscious state: Results from a national study

BRAIN INJURY | Online article – 9 May 2012 – The aim of this study is to evaluate the burden of caregivers of patients with disorders of consciousness (DOCs), considering psychosocial difficulties, health condition and financial aspects. Results showed a high burden related to providing care to patients with DOCs. This study sets the scene to plan comprehensive support strategies... <http://informahealthcare.com/doi/abs/10.3109/02699052.2012.667589>

Don't dodge the difficult conversation, says new report

BRITISH JOURNAL OF CARDIOLOGY | Online report – 17 May 2012 – Palliative care for cancer patients in the U.K. is well established – but the situation is starkly different for those suffering from heart failure. A recent service evaluation led by the University of Hull and Hull York Medical School shows this doesn't have to be the case – particularly if clinicians have the courage to talk about death with their patients. The study ... describes data from two areas in Yorkshire where palliative care and heart failure services are fully integrated... Results show that integrated team work can reduce unwanted hospital deaths for heart failure patients, enabling many to die where they prefer. The study was led by Dr. Miriam Johnson ... [who said] ... "There's long been a perception that you can't talk to heart failure patients about death mainly because it's seen as difficult to predict when patients are close to end of life. However, our work shows that many heart failure patients are able to have honest discussions with their clinicians about their prognosis and appreciate the opportunity it provides for them to make plans and set their affairs in order." The team found that heart failure specialist nurses were able to recognise when patients were nearing end of life in the vast majority of cases and discuss the issues with them. Over two thirds of patients put plans in place for end of life and stated where they wished to die – most choosing to be at home – and their preferred place of death was achieved in 61% of cases. Over half of all patients accessed specialist care services compared to the 2011 National Audit Office figures of just 4% overall in the U.K., but Dr. Johnson stresses that the national figures are not completely reliable. http://www.sciencecodex.com/dont_dodge_the_difficult_conversation_says_new_report-91691

N.B. Source: Science Codex. Link to journal article unavailable at the time this issue of Media Watch was distributed.

Of related interest:

- *HEALTH COMMUNICATIONS* | Online article – 10 May 2012 – '**Beyond good intentions and patient perceptions: Competing definitions of effective communication in head and neck cancer care at the end of life.**' Study participants rated their oncologists as competent and comfortable discussing end-of-life issues, although few reported discussing specific aspects of end-of-life care. Oncologists viewed giving prognostic information as a process rather than a singular event, and preferred answering patients' questions as opposed to guiding the discussion. These data reveal subtle disconnects in communication suggesting patients' and health care providers' information needs are not being met. <http://www.tandfonline.com/doi/abs/10.1080/10410236.2012.666957>

Advance directives?

Medical ink

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online report – 14 May 2012 – If your spouse's initials are "D.N.R.," you should probably think twice before tattooing them on your chest. Then again, if your end-of-life plans include a do-not-resuscitate order, maybe it's not such a bad idea after all. It appears the tattoo craze has expanded beyond mere aesthetics into medicine. Some people are setting down advance directives on skin in addition to paper. Others are opting for tattoos on their wrists instead of MedicAlert bracelets, favouring ink over jewelry. Though there are advantages to turning your epidermis into a medical record – you can't accidentally leave your forearm at home – some health professionals fear that paramedics and emergency physicians might not notice the tattoos, let alone treat them as proper instructions. http://www.cmaj.ca/site/earlyreleases/14may12_medical-ink.xhtml

From Media Watch, 19 March 2012:

- U.S. (CALIFORNIA) | *North County Times* – 11 March 2012 – "**No CPR' tattoo a waste of good ink.**" http://www.nctimes.com/news/opinion/commentary/forum-no-cpr-tattoo-a-waste-of-good-ink/article_ddd86ce4-fb09-5319-9bca-c6ac2363fda0.html

Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making

HEALTH AFFAIRS, 2012;31(5):1030-1038. Relatively little is known about why some patients are reluctant to engage in a collaborative discussion with physicians about their choices in health care. In the focus groups, the authors found that participants voiced a strong desire to engage in shared decision making about treatment options with their physicians. However, several obstacles inhibit those discussions [including] the fact that even relatively affluent and well-educated patients feel compelled to conform to socially sanctioned roles and defer to physicians during clinical consultations; that physicians can be authoritarian; and that the fear of being categorized as "difficult" prevents patients from participating more fully in their own health care. They argue physicians may not be aware of a need to create a safe environment for open communication to facilitate shared decision making. Rigorous measures of patient engagement, and of the degree to which health care decisions truly reflect patient preferences, are needed to advance shared decision making in clinical practice. <http://content.healthaffairs.org/content/31/5/1030.abstract>

The experiences and care preferences of people with diabetes at the end of life: A qualitative study

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2012;14(4):293-302. Five key themes were identified [in this study]: 1) living with diabetes; 2) sometimes they "bugger it up"; 3) it is a complicated subject; 4) when I am very ill; and, 5) plans for the very end. Findings suggest that health professionals should continue monitoring blood glucose levels when a person has a life-limiting illness, listen to the views of the person with diabetes about his/her diabetes management, and identify and acknowledge the patient's diabetes management preferences when he/she is very ill. http://journals.lww.com/jhpn/Abstract/2012/06000/The_Experiences_and_Care_Preferences_of_People.10.aspx

Withdrawal of life-sustaining treatment from a patient in a minimally conscious state

JOURNAL OF LAW & MEDICINE, 2012;19(3):430-435. This column reports on a recent decision, the first in England in which a court was asked to authorise the withdrawal of artificial nutrition and hydration from a patient in a "minimally conscious state." Since the seminal decision in 1993 in *Airedale NHS Trust v Bland* [1993] AC 789, in which the House of Lords authorised withdrawal of artificial nutrition and hydration from a patient in a persistent vegetative state, the relatively new diagnosis of a "minimally conscious state" has been recognised. In deciding whether it was in the patient's best interests that artificial nutrition and hydration be withdrawn and withheld, the court made a key legal determination, with precedential effect, as to whether the so-called "balance sheet" approach to determining a patient's best interests, as opposed to the (discredited) "futility" principle, applies to a patient in a minimally conscious state. The merit of the former approach is that it forces explicit consideration of quality-of-life assessments in favour of and against withdrawing life-sustaining treatment. A significant pitfall of the English position, as it is currently developing, is the premium it places on accurate diagnosis, whether of vegetative state or minimally conscious state. These issues will have to be faced sooner or later by Australasian courts. <http://www.ncbi.nlm.nih.gov/pubmed/22558896>



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>

What can we learn about the spiritual needs of palliative care patients from the research literature?

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online article – 11 May 2012 – Spirituality is a distinctive subject within palliative care practice and literature, but research to date is relatively undeveloped in this field and studies often throw more light on conceptual and methodological issues than producing reliable data for clinical practice. Thirty-five studies were identified, equating to a total of 1374 patients. Study populations were typically people with advanced-stage cancer, older than 60 years, who are English speaking, and with a Christian or Jewish religious affiliation, reflecting the predominance of Anglo-American studies. Studies fell into two groups: those that investigated the nature of spiritual experience and those that examined the relationship of spirituality with other phenomena. The evidence was insufficiently homogeneous to pool. Relevant accounts of what spirituality means for palliative care patients and evidence of how it operates in the lives of people with life-limiting disease can be derived from research. Studies to date are limited by reductive representations of spirituality and the conduct of research by health professionals within health care communities demarcated from disciplines and interpretive traditions of spirituality. [http://www.jpsmjournal.com/article/S0885-3924\(11\)00870-0/abstract](http://www.jpsmjournal.com/article/S0885-3924(11)00870-0/abstract)

Of related interest:

- *COCHRANE DATABASE OF SYSTEMATIC REVIEWS* | Online article – Accessed 15 May 2012 – '**Spiritual and religious interventions for well-being of adults in the terminal phase of disease.**' The authors found inconclusive evidence that interventions with spiritual or religious components for adults in the terminal phase of a disease may or may not enhance well-being. Such interventions are under-evaluated. All five studies identified were undertaken in the same country, and in the multi-disciplinary palliative care interventions it is unclear if all participants received support from a chaplain or a spiritual counsellor. <http://discovery.ucl.ac.uk/1347180/>

National survey of children's hospitals on legacy-making activities

JOURNAL OF PALLIATIVE MEDICINE, 2012;15(5):573-578.. Nearly all providers surveyed reported offering legacy-making activities to ill children and their families, with patients and families usually completing the activity together. Most activities were offered before a patient died and when cure is no longer being sought. Perceived outcomes included benefit to bereaved families and a tangible memento of their deceased child. Legacy-making may enhance life and decrease suffering for dying children and their families. Healthcare professionals can facilitate opportunities for children and their families to build legacies. Additional research is needed to examine activities across different age groups and conditions, the best time to offer such activities, and associations with positive and negative outcomes for ill children, their family members, and the bereaved. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0447>

Evolution of end-of-life care at U.S. hospitals in the new millennium

JOURNAL OF PALLIATIVE MEDICINE, 2012;15(5):592-601. The number of DTH [discharge to hospice] per year increased 15 fold from 27,912 in 2000 to 420,882 in 2009. The median hospital stay decreased, while the median age, proportion of sepsis disease related groups (DRGs), and proportion of Medicare hospitalizations increased. Lung, gastrointestinal, hepato-biliary, and brain cancer were consistently the most prevalent malignancy DRGs. However, the initial preponderance of hospitalizations with any diagnosis of cancer was diminished by the end of the study. Female gender, age, and chronic obstructive pulmonary disease were predictors of discharge to hospice, while congestive heart failure was inversely associated. Hospital discharges to hospice have increased over the past ten years, with a concomitant shift in clinical and demographic characteristics. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0432>

The dialogue about death and dying: It's time

NURSING ECONOMICS, 2012;30(3):122,147. Leading change and advancing the health of the nation requires courage and great risks. As we await the outcome of the Supreme Court's decision on the Affordable Care Act, and confront the rising fear of unexpectedly slow economic recovery and high unemployment, it is time to have the leadership, courage, and risk to dialogue about death and death. The crisis, costs, and politics caused by unattended health care issues, in this case, the escalating costs incurred at the end-of-life as well as the difficulty most individuals experience while discussing death has created the "perfect storm." With the recent release of the Institute of Medicine report on The Future of Nursing (2010) and the call for nurses to lead and advance health, *Nursing Economic* has chosen to manage the storm's chaos with a special issue dedicated to examining "How can we afford to die?"¹ This issue demonstrates the best evidence from nurse leaders on and about the end-of-life topic, including care and costs.

http://www.nursingconomics.net/necfiles/specialissue/2012/editorial_Nickitas.pdf

1. *Nursing Economics* Contents page:
http://www.nursingconomics.net/cgi-bin/WebObjects/NECJournal.woa/wa/viewSection?s_id=1073744460

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 14 May 2012 – **'The practical nurse: A case for COMFORT curriculum training.'**
<http://ajh.sagepub.com/content/early/2012/05/09/1049909112446848.abstract>
- *INTERNATIONAL JOURNAL OF NURSING STUDIES* | Online article – 7 May 2012 – **'Nurses' early experiences with patient death: The results of an on-line survey of registered nurses in New Zealand.'**
<http://www.sciencedirect.com/science/article/pii/S0020748912001435>
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2012;14(4):293-302. **'Facilitating goals-of-care discussions for patients with life-limiting disease – communication strategies ...'**
http://journals.lww.com/jhpn/Abstract/2012/06000/Facilitating_Goals_of_Care_Discussions_for.3.aspx
- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 14 May 2012 – **'The art versus science of predicting prognosis: Can a prognostic index predict short term mortality better than experienced nurses do?'** <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0531>
- *NURSE EDUCATION TODAY* | Online article – 5 May 2012 – **'The impact of spiritual care education upon preparing undergraduate nursing students to provide spiritual care.'**
<http://www.sciencedirect.com/science/article/pii/S0260691712001104>
- *NURSING TIMES* (U.K.) | Online report – 15 May 2012 – **'Nurses should be recruited on 'caring' values.'** <http://www.nursingtimes.net/nursing-practice/clinical-specialisms/educators/nurses-should-be-recruited-on-caring-values/5044695.article>

Life-sustaining treatment decisions in the ICU for patients with ESLD: A prospective investigation

RESEARCH IN NURSING & HEALTH | Online article – 11 May 2012 – The overarching theme describing the decision-making process was "on the train." Four sub-themes positioned patients and family members [i.e., study participants] as passengers with limited control, unable to fully understand the decision-making process. Findings suggest that including patients and family members in non-immediate life-saving decisions and verifying early on their understanding may help to improve the decision-making process.
<http://onlinelibrary.wiley.com/doi/10.1002/nur.21488/abstract>

A pilot training programme for health and social care professionals providing oncological and palliative care to lesbian, gay and bisexual patients in Ireland

PSYCHO-ONCOLOGY | Online article – 9 May 2012 – With the exception of a programme in the U.S., there is a lack of training internationally for health and social care professionals providing oncological and palliative care to LGB [lesbian, gay and bisexual] patients. In Ireland, a training project ... developed a pilot programme for health and social care professionals providing oncological and palliative care to LGB patients. The majority of participants reported that they would recommend the training to their colleagues, were interested in further training in the area and found the training useful for their practice. They also reported becoming more familiar with LGB-related language and terminology, became more knowledgeable of LGB health issues and reported becoming more confident in providing care to LGB patients.

<http://onlinelibrary.wiley.com/doi/10.1002/pon.3103/abstract;jsessionid=320C7DC961CC7C013CA6AE1FAA27F292.d02t02?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

From Media Watch, 9 April 2012:

- *CULTURE, HEALTH & SEXUALITY* | Online article – 2 April 2012 – '**End-of-life care for gay, lesbian, bisexual and...**' <http://www.tandfonline.com/doi/abs/10.1080/13691058.2012.673639>

From Media Watch, 19 March 2012:

- U.K. | National Council for Palliative Care report – 15 March 2012 – '**End of life care services letting down lesbian, gay, bisexual and transgender people...**' <http://www.ncpc.org.uk/news/87>

From Media Watch, 6 February 2012:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2012;18(1):29-34. '**End-of-life care considerations for gay, lesbian, bisexual, and transgender...**' http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=89126;article=IJPN_18_1_29_34

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.

Entering a world without future: A phenomenological study describing the embodied experience of time when living with severe incurable disease

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online article – Accessed 15 May 2012 – This paper presents findings from a phenomenological study exploring experience of time by patients living close to death. Three aspects of experience of time were revealed as prominent: 1) entering a world with no future [and] living close to death alters perception of and relationship to time; 2) listening to the rhythm of my body, not looking at the clock, embodied with severe illness [and] it is the body not the clock that structures and controls the activities of the day; 3) receiving time, taking time, being offered not asked for help, is like receiving time that confirms humanity [and] in contrast to having to ask for help which is like taking others time and thereby revealing own helplessness. Experience of time close to death is discussed as an embodied experience of inner, contextual, relational dimensions in harmony and disharmony with the rhythm of nature, environment and others. Rhythms in harmony provide relief, while rhythms in disharmony, confer weakness and limit time. <http://nu.diva-portal.org/smash/record.jsf?pid=diva2:523709>

One more chemo or one too many: Defining the limits of treatment and innovation in medical oncology

SOCIAL SCIENCE & MEDICINE | Online article – 14 May 2012 – Within bioethics, some writers have put forward a number of principles for judging the legitimacy of medical interventions, notably that of patient autonomy. Broad social and political developments have also profoundly affected medical practices at the end of life. Though therapeutic options have evolved, whether to stop or to pursue treatment in the face of certain death has been a central issue in medical oncology since the early 1950s. A critical appraisal of the history of this issue can help us to better understand the tangled relationship(s) between innovation, "cure," death, and the symptoms and subjective experiences of sufferers. This paper addresses an aspect of this complex problem, namely how limits are established regarding both treatment and therapeutic innovation near the end of life. Utilizing a grounded theory and situational analysis approach it traces how the issues at stake were defined and the ways in which the dilemma was progressively transformed as a result of the combined effects of a proliferating number of stakeholders, molecules, instruments, and techniques. It discusses three different moments, as they epitomize how the links between chemotherapy and palliation were construed through the evolving forms of clinical research and innovative therapies. <http://www.sciencedirect.com/science/article/pii/S0277953612002900?v=s5>

From Media Watch, 27 February 2012:

- U.K. | *Daily Mail* – 21 February 2012 – **'Give up chemo? No way. I owe it to my children to fight for every day of life.'** <http://www.dailymail.co.uk/health/article-2103983/Give-chemo-No-way-I-owe-children-fight-day-life.html?ito=feeds-newsxml>

From Media Watch, 3 February 2012:

- *JOURNAL OF CLINICAL ONCOLOGY* | Online article – 7 February 2012 – **'Palliative care: A lifeline to quality of life.'** Promoting quality of life and preventing suffering are essential aspects of practice for clinicians whose ambition it is to deliver high-quality cancer care. The American Society of Clinical Oncologist's Provisional Clinical Opinion (PCO)¹ offers the opportunity to bring clinicians a significant step forward in delivering truly patient-centered, family-focused care that can make a difference. <http://jop.ascopubs.org/content/early/2012/02/07/JOP.2011.000530.full.pdf+html>

1. 'American Society of Clinical Oncology provisional clinical opinion: The integration of palliative care into standard oncology care,' *Journal of Clinical Oncology*, published online 6 February 2012. <http://jco.ascopubs.org/content/early/2012/02/06/JCO.2011.38.5161.abstract>

Worth Repeating

Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives loss of continuity and lack of closure

ARCHIVES OF INTERNAL MEDICINE, 2009;169(5):474-479. Surveys and anecdotes suggest that patients and family members sometimes feel abandoned by their physicians at the transition to end-of-life care. To the authors' knowledge, no prior studies describe abandonment prospectively. Two themes were identified [in this longitudinal, qualitative study]: before death, abandonment worries related to loss of continuity between patient and physician; at the time of death or after, feelings of abandonment resulted from lack of closure for patients and families. Physicians reported lack of closure but did not discuss this as abandonment. Framing this professional value as continuity and closure could promote the development of interventions to improve this aspect of end-of-life care. <http://archinte.ama-assn.org/cgi/content/abstract/169/5/474>

Media Watch Online

The weekly report can be accessed at several websites, among them:

Canada

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

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

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

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

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

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (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: barryashpole@bellnet.ca