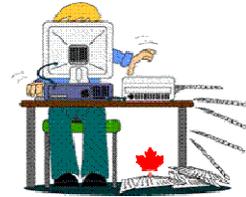


## Media Watch...

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.

26 March 2012 Edition | Issue #246



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

Compiled & Annotated by Barry R. Ashpole

**Advancing elder care: Scroll down to [Specialist Publications](#) and 'Guidelines for nursing homes delivering end-of-life care to residents with dementia across the island of Ireland' (p.10), published in *Quality in Ageing & Older Adults*.**

## Canada

### Patients living with HIV are dying in denial

ONTARIO | *Toronto Star* – 23 March 2012 – In a country such as Canada, with decades of readily available treatment for HIV and clinics and programs devoted to the disease, the stigma and shame associated with the virus continues to be a barrier, HIV experts say. HIV advocates and physicians say they still encounter people with the disease who don't seek treatment, increasing their risk of death and spread of the disease. By the time they go to hospital, they have deeply compromised immune systems, and sometimes full-blown AIDS. An estimated 65,000 people in Canada (26,630 in Ontario) were living with HIV in 2008, the most recent figures available through the Public Health Agency of Canada. It is also estimated that nearly 17,000 of those people are unaware of their status. What isn't known is how many of those individuals who test positive for HIV do not seek treatment, although an Ontario study last year found one in 10 men and one in 14 women had not gone for viral-load testing a year after being newly diagnosed. The test, which measures the amount of HIV in one's blood, should be

done every three to four months to determine the need for anti-retroviral drugs. <http://www.thestar.com/living/article/1146163--patients-living-with-hiv-are-dying-in-denial?bn=1>

#### Extract from *Toronto Star* article

Earlier this month, an American study<sup>1</sup> found one in four people with HIV do not stay in care, the first comprehensive nation-wide look at patients and their willingness to seek treatment over time. "Our findings show too many patients are falling through the cracks," said lead author Baligh Yehia, a fellow at the Perelman School of Medicine at the University of Pennsylvania. The research suggests the findings will help doctors assess why patients avoid treatment and devise strategies to ensure people seek care.

1. 'Comparing different measures of retention in outpatient HIV care,' *AIDS*, published online 29 February 2012. [http://journals.lww.com/aidsonline/Abstract/publishahead/Comparing\\_different\\_measures\\_of\\_retention\\_in\\_98963.aspx](http://journals.lww.com/aidsonline/Abstract/publishahead/Comparing_different_measures_of_retention_in_98963.aspx)

## Sometimes, for the frail elderly, the less medical intervention, the better

NOVA SCOTIA | *Globe & Mail* (Halifax) – 18 March 2012 – The frail and elderly, it has been said, consume too many health services, languish in hospital beds, then die in them. But maybe the problem is that few explain the risks of medical interventions or offer them a better death. Instead of herding the frail elderly through hospital, one Nova Scotia program informs them of their risks, after an assessment: among them, cognitive decline and loss of mobility. Since the 200 or so patients fitting the definition of "frail and elderly" have gone through this program since 2009 ... there has been a 76% reduction in interventions. "We help them understand the pros and cons of even simple treatments," said Dr. Paige Moorhouse, who [with Dr. Laurie Mallery] co-founded the palliative and therapeutic harmonization program [PATH] at Dalhousie University and the QEII Health Sciences Centre. Some forgo operations and choose medication instead. Others have modest goals of staying at home, not wanting to return to hospital. Some charge on with the intervention. All eventually face a health crisis that prompts them to decide how much treatment is too much. <http://www.theglobeandmail.com/news/opinions/editorials/sometimes-for-the-frail-elderly-the-less-medical-intervention-the-better/article2373292/>

From Media Watch, 27 December 2010:

- NOVA SCOTIA | *Chronicle-Herald* (Halifax) – 21 December 2010 – '**A place to find comfort.**' The [Palliative & Therapeutic Harmonization] clinic isn't about limiting treatments ... but rather taking a comprehensive look at the multiple conditions of these "frail" elderly patients and how treating one illness might actually hurt another. Clinic staff try to help patients with this "illness burden" weigh all the risks before they make a decision. <http://thechronicleherald.ca/ArtsLife/1218300.html>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *Montreal Gazette* – 23 March 2012 – '**Medical aid' to die endorsed.**' A committee of the National Assembly unanimously recommended ... that rules be established to shelter from prosecution doctors who offer terminally ill patients "medical assistance to die." The Criminal Code of Canada prohibits euthanasia, making it an offence to counsel or assist someone to commit suicide, or to agree to be put to death. But the committee, composed of members from all parties in the assembly, has proposed that Quebec's attorney-general issue a directive so that doctors who help someone die would not be prosecuted – provided the doctors respect a series of conditions Quebec would legislate. The report noted this is what Quebec did in 1976, when the province's attorney-general ordered an

end to prosecutions for abortion. Abortions remained a criminal offence in Canada until 1988, but prosecutions in Quebec ceased 12 years earlier, and other provinces followed its example. <http://www.montrealgazette.com/news/Medical+endorsed/6346082/story.html>

Apart from essential definitions and legal concepts, the committee's report includes two main sections. The first discusses end-of-life care and deals with the questions of refusal and cessation of treatment, palliative care, palliative sedation and planning for end-of-life care in the case of incapacity. The second presents the results of the committee members' reflection on euthanasia. More specifically, it describes the context, the arguments for and against the practice and explains the position of the committee members.

**N.B.** At the time of distributing this week's edition of Media Watch, only the French language version of the committee's report ('La Commission spéciale sur la question de mourir dans la dignité dépose son rapport') was available: [http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller\\_120323\\_soins-palliatifs/?lang=en](http://www.gouv.qc.ca/portail/quebec/pgs/commun/actualites/actualite/asurveiller_120323_soins-palliatifs/?lang=en)

## U.S.A.

### **I've accepted I'm dying. Now what?**

*FORBES* | Online article – 23 March 2012 – The emotional part of the realization you are going to die is nothing anyone can prepare you for. Even though you knew it was a possibility, it is still a numbing shock. Your mind obsesses over little things, some important, most not important. Without knowing how much time you have left, or how sick you will feel, paralysis becomes the overwhelming reaction. What and how much can you get done in this situation? Hopefully, you have involved a palliative care team or hospice in your care. If not, make that call immediately. This will make it easier to take care of all your other important matters. Precious things matter first, and for most of us, that would be our friends and family. When you

are dying, the last thing you may think about is how you make people feel. However, the last memory of you is an important one they will carry forever, so tell your family and friends how much you love them.

<http://www.forbes.com/sites/carolynmclanahan/2012/03/23/ive-accepted-im-dying-now-what/>

#### **Extract from *Forbes* article**

As Maya Angelou said, "I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."

### Vulnerable populations

#### **Idaho prison's health care called 'inhumane'**

IDAHO | *Spokesman-Review* (Spokane, Washington) – 20 March 2012 – Medical care is so poor at an Idaho state prison that it amounts to neglect and cruel and unusual punishment, according to a report that was unsealed Monday. Correctional health care expert Dr. Marc Stern said there have been some improvements at the Idaho State Correctional Institution south of Boise. But terminal and long-term inmates sometimes went unfed, nursing mistakes or failure likely resulted in some deaths, and one inmate wasn't told for seven months that he likely had cancer. The Idaho Department of Correction and the prison health care provider, Brentwood, Tennessee-based Corizon, said they're disappointed and are preparing a response that will show the care delivered to inmates meets constitutional and health care standards. Stern was appointed to study the

care at the prison near Boise as part of a long-running lawsuit brought by inmates. A federal judge is expected to consider the report as he decides whether to allow the lawsuit to continue or bring it to a close.

<http://www.spokesman.com/stories/2012/mar/20/idaho-prisons-health-care-called-inhumane/>

#### **Extract from *Spokesman-Review* article**

Some of the medical problems described in the report are disturbing, including Stern's findings that inmates who were terminal or required long-term care and who were unable to move on their own were sometimes left in soiled linens, given inadequate pain medication and went periods without food and water.

#### **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>

## End-of-life care home to open for those facing death alone

CALIFORNIA | *Ventura County Star* (Camarillo) – 16 March 2012 – Our Community House of Hope is one of a handful of care homes in the nation designed to provide care and support for needy people facing death alone. After more than six years of planning, the opening comes at a time when growing numbers of terminally ill people are isolated, social service officials say. <http://www.vcstar.com/news/2012/mar/16/end-of-life-care-home-to-open-for-those-facing/>

## International

### Doctors must be trained in care of the dying: Report<sup>1</sup>

U.K. | *Daily Telegraph* – 22 March 2012 – Doctors need to identify when people are 'entering the last phase of life' much earlier and have discussions with them about the care they want to receive. Too often hospital doctors treat the patient for their current problem and recognise that they are dying too late for alternative care arrangements in a hospice or at home to be made. The Royal College of Physicians has recommended that all hospital doctors, whose role involves care for the dying, should go on a training course every five years. Currently only cancer doctors have to go on mandatory training after qualifying and guidance says it need only be once in their careers. <http://www.telegraph.co.uk/health/healthnews/9157831/Doctors-must-be-trained-in-care-of-the-dying-report.html>

1. 'Improving end-of-life care: Professional development for physicians – a report of a working group,' Royal College of Physicians, March 2012. <http://www.rcplondon.ac.uk/sites/default/files/improving-end-of-life-care.pdf>

### 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.hpconnection.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')

#### **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>

## **Alcohol abuse contributes to big rise in deaths from liver disease**

U.K. (ENGLAND) | *Guardian* – 22 March 2012 – The first report from the NEoLCIN warns that the victims of liver disease are getting younger, with deaths increasing among people in their forties.<sup>1</sup> Deaths rose from 9,231 in 2001 to 11,575 in 2009; some 60% of these were men, and 90% of them were under 70. Deaths are more common in England's northern regions marked by high unemployment and low educational achievement. The figures for causes of death between 2001 and 2009 show a general decline in other major causes, such as heart disease, but the report acknowledged that cancer and vascular and respiratory conditions were still the big killers. However, more than one in 10 deaths among people in their forties followed a liver condition, and its place in the medical league table of "years of life lost" is high: 37% of liver disease

deaths for people in their forties were alcohol related, split 41% for men and 30% for women. <http://www.guardian.co.uk/society/2012/mar/22/alcohol-rise-deaths-liver-disease>

### **Extract from the NEoLCIN report**

There are a number of reasons why end of life care for people with liver disease is particularly challenging. Patients tend to be younger and often come from either isolated or ethnically diverse subcultures. They are more likely to have come to healthcare attention by circuitous routes of access. They may feel great stigma associated with their disease, the progress of which is punctuated by acute exacerbations. Most of all, perhaps, it is challenging because the cause of their death may have been preventable.

1. 'Deaths from liver disease: Implications for end of life care in England,' National End of Life Care Intelligence Network, March 2012. [http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths\\_from\\_liver\\_disease.aspx](http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_liver_disease.aspx)

## **Palliative care in India**

### **Palliative care project inaugurated**

INDIA (KERALA) | IBN Live (Thiruvananthapuram) – 21 March 2012 – In a novel move, the City Corporation has launched its project to extend palliative care to the ailing in the city. Under the project, palliative care volunteers trained by the Corporation would visit homes of cancer patients and others who need help physically and mentally to attend to their needs. The project is being implemented in five hospitals. <http://ibnlive.in.com/news/palliative-care-project-inaugurated/241321-60-123.html>

### **Forty children's hospices to benefit from grant**

U.K. | Department of Health – 20 March 2012 – Forty children's hospices will receive a share of the Department's annual £10 million Children's Hospice & Hospice-at-home grant. The Government pledged to provide £10 million annually to support voluntary sector provision of children hospices and hospice at home care until 2015 when new funding arrangements are expected to be in place. The new funding system will be informed by pilots, which have been set up to gather evidence and test the recommendations of the Independent Palliative Care Funding Review.<sup>1,2</sup> <http://www.dh.gov.uk/health/2012/03/announcement-of-grant-for-40-children%E2%80%99s-hospices/>

1. '£1.8 million for fairer funding for end of life care,' Department of Health, 21 March 2012. <http://www.egovmonitor.com/node/48194>
2. 'Funding the right care and support for everyone,' July 2011 (noted in Media Watch, 4 July 2011). [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_133105.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_133105.pdf)

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Observer* – 25 March 2012 – '**Assisted dying policy put to Commons vote.**' MPs will be asked to endorse guidance that distinguishes between compassionate assistance and 'malicious encouragement.' <http://www.guardian.co.uk/society/2012/mar/25/commons-debate-euthanasia-law?newsfeed=true>
- U.K. (NORTHERN IRELAND) | *News Letter* (Belfast) 22 March 2012 – '**Public can decide over euthanasia – Nesbitt.**' The Ulster Unionist leadership contest has moved into ethical questions after front-runner Mike Nesbitt suggested there should be a referendum on whether to legalise euthanasia. Asked during an interview on BBC Radio Ulster's Nolan Show for his views on a patient with an incurable disease who wants to be killed ... Mr. Nesbitt said that it was an issue for the public rather than politicians to decide. <http://www.newsletter.co.uk/news/public-can-decide-over-euthanasia-nesbitt-1-3651352#>

### 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.



### 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>

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

### **To tell the truth, the whole truth, may do patients harm: The problem of the nocebo effect for informed consent**

*AMERICAN JOURNAL OF BIOETHICS* | Online article – 14 March 2012 – The principle of informed consent obligates physicians to explain possible side effects when prescribing medications. This disclosure may itself induce adverse effects through expectancy mechanisms known as nocebo effects, contradicting the principle of non-maleficence. Rigorous research suggests that providing patients with a detailed enumeration of every possible adverse event – especially subjective self-appraised symptoms – can actually increase side effects. Describing one version of what might happen (clinical "facts") may actually create outcomes that are different from what would have happened without this information (another version of "facts"). This essay argues that the perceived tension between balancing informed consent with non-maleficence might be resolved by recognizing that adverse effects have no clear black or white "truth." This essay suggests a pragmatic approach for providers to minimize nocebo responses while still maintaining patient autonomy through "contextualized informed consent," which takes into account possible side effects, the patient being treated, and the particular diagnosis involved.  
<http://www.tandfonline.com/doi/abs/10.1080/15265161.2011.652798>

#### **Why physicians ought to lie for their patients**

*AMERICAN JOURNAL OF BIOETHICS* | Online article – 14 March 2012 – Sometimes physicians lie to third-party payers in order to grant their patients treatment they would otherwise not receive. This strategy, commonly known as gaming the system, is generally condemned for three reasons. First, it may hurt the patient for the sake of whom gaming was intended. Second, it may hurt other patients. Third, it offends contractual and distributive justice. Hence, gaming is considered to be immoral behavior. This article is an attempt to show that, on the contrary, gaming may sometimes be a physician's duty. Under specific circumstances, gaming may be necessary from the viewpoint of the internal morality of medicine. Moreover, the objections against gaming are examples of what we call the idealistic fallacy, that is, the fallacy of passing judgments in a non-ideal world according to ideal standards. Hence, the objections are inconclusive. Gaming is sometimes justified, and may even be required in the name of beneficence.  
<http://www.tandfonline.com/doi/abs/10.1080/15265161.2011.652797>

**N.B.** This article is followed by 'Open Peer Commentaries' on the same topic. Journal contents page:  
<http://www.tandfonline.com/toc/uajb20/current>

**N.B.** This article is followed by 'Open Peer Commentaries' on the same topic. Journal contents page:  
<http://www.tandfonline.com/toc/uajb20/current>

Of related interest:

- *BMC MEDICAL EDUCATION* | Online article – 24 March 2012 – '**Enhancing medical students' communication skills: Development and evaluation of an undergraduate training program.**' Students who attended the communication skills course exhibited a considerable increase of communication skills in this newly developed training. It was also observed that students in the intervention group had a greater degree of self-assessed competence following training than the medical students in the comparison group. <http://www.biomedcentral.com/content/pdf/1472-6920-12-16.pdf>
- *THE HOSPITALIST* (U.S.) | Online report – 21 March 2012 – '**New report highlights importance of physician communication training.**' A new report<sup>1</sup> shows that not all physicians agree on how forthcoming they should be with patients, but this should not be viewed by the public as evidence that most doctors lie. <http://www.the-hospitalist.org/view/0/index.html>

1. 'Survey shows that at least some physicians are not always open or honest with patients,' *Health Affairs*, 2012;31(2):383-391 (noted in Media Watch, 13 February 2012).  
<http://content.healthaffairs.org/content/31/2/383.abstract>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online article – 20 March 2012 – '**Intensive communication skills teaching for specialist training in palliative medicine: Development and evaluation of an experiential workshop.**' The Australasian Chapter of the Palliative Medicine Curriculum Development Group identified communication as a core skill that trainees in palliative medicine need to acquire, and proposed the development of a communication skills workshop that should become a compulsory part of training to achieve accreditation as a palliative medicine specialist in Australia and New Zealand. This paper describes the development and subsequent evaluation of this module. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0292>

### **Palliative care has much to bring to geriatric psychiatry**

*AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY*, 2012;20(4). This issue highlights similarities and relationships between geriatric psychiatry and palliative care. In an editorial summarizing the issues, [Scott] Irwin points out that the overarching goal of both palliative care and geriatric psychiatry is to improve the quality of life for patients and their families. This goal is accomplished by treating the whole patient, not just their diagnoses or symptoms, and focusing on common psychiatric syndromes that geriatric and hospice populations often face, such as depression and delirium. Journal contents page: <http://journals.lww.com/ajgponline/pages/currenttoc.aspx>

From Media Watch, 29 August 2011:

- *PEDIATRIC CLINICS OF NORTH AMERICA*, 2011;58(4):1025-1039. '**Partnerships between pediatric palliative care and psychiatry.**' The authors present an overview of pediatric palliative care followed by a summary of some of the roles for psychiatry. Two innovative pediatric palliative care programs that psychiatrists may or may not be aware of are described. Finally, some challenges that are faced in further developing this partnership and suggestions for future research are discussed. [http://www.pediatric.theclinics.com/article/S0031-3955\(11\)00062-9/abstract](http://www.pediatric.theclinics.com/article/S0031-3955(11)00062-9/abstract)

From Media Watch, 23 May 2011:

- *MEDSCAPE* | Online interview – 10 May 2011 – '**Palliative care psychiatry: What is it and does it work?**' Because patients with advanced life-threatening illnesses can have complex psychiatric issues and are often referred to palliative care teams, these teams need access to psychiatry and psychiatrists as consultants to provide exquisite interdisciplinary palliative care that addresses the complexities of this burden of suffering. <http://www.medscape.com/viewarticle/741903>

### **Comparing the needs of families of children dying from malignant and non-malignant disease: An in-depth qualitative study**

*BMJ SUPPORTIVE & PALLIATIVE CARE* – 24 March 2012 – Community-based services for children and young people with cancer at the end of life were perceived by parents as responsive to parent and child needs. Conversely, community services for children and young people with non-malignant conditions were experienced as *ad hoc* and under-resourced. Community services for children with non-malignant conditions may require further development if they are to meet the levels of support offered to parents of children with cancer. If improvement is to be achieved, the need to raise awareness regarding hospice services, hospice referral and eligibility criteria across the entire gamut of service providers is essential.

<http://spcare.bmj.com/content/early/2012/03/24/bmjspcare-2011-000104.abstract>

Of related interest:

- *SINGAPORE MEDICAL JOURNAL*, 2012;53(3):192-195. '**Do children die? A retrospective review of deaths in a children's hospital.**' The authors present a profile of deaths over two years in the medical departments of a children's hospital ... [to] ... better understand the individual dying experience of these patients. Service gaps and ways to optimise provision of supportive care were identified in the process. <http://smj.sma.org.sg/5303/5303a7.pdf>

## **Bereavement interventions, end-of-life cancer care, and spousal well-being: A systematic review**

*CLINICAL PSYCHOLOGY* | Online article – 20 March 2012 – Recent comprehensive reviews have concluded that there is little evidence for the effectiveness of bereavement interventions. These reviews have not been limited to investigations of bereavement services for spouses of patients with cancer. This systematic review examined the evidence from 10 articles reporting on eight studies examining outcomes of bereavement interventions and adjustment to bereavement following specialized end-of-life patient care for spouses of patients with cancer. Patient end-of-life interventions may positively influence bereavement outcomes for spouses, but based on the available evidence, it is difficult to draw definitive conclusions about the effectiveness of bereavement group interventions for spouses of patients with cancer. Methodologically rigorous studies with larger sample sizes are required to determine the effectiveness of these interventions. <http://onlinelibrary.wiley.com/doi/10.1111/j.1468-2850.2012.01275.x/abstract?userIsAuthenticated=false&deniedAccessCustomisedMessage=>

## **Family caregiver participation in hospice interdisciplinary team meetings: How does it affect the nature and content of communication?**

*HEALTH COMMUNICATION* | Online article – 21 March 2012 – The purpose of this study was to explore team communication when video-conferencing is used to facilitate the family caregiver's participation in a hospice team meeting. Video-recorded team meetings with and without family caregiver participation were analyzed for communication patterns using the Roter Interaction Analysis System. Standard meetings that did not include caregivers were shorter in duration and task-focused, with little participation from social workers and chaplains. Meetings that included caregivers revealed an emphasis on biomedical education and relationship-building between participants, little psychosocial counseling, and increased socio-emotional talk from social workers and chaplains. Implications for family participation in hospice team meetings are highlighted. <http://www.tandfonline.com/doi/abs/10.1080/10410236.2011.652935>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – 24 March 2012 – '**Supporting family caregivers of hospitalised palliative care patients: a psychoeducational group intervention.**' This study reinforces the notion that psycho-educational interventions for this population can potentially be applicable, acceptable and effective. However, the number of participants who were recruited and attended each session was fewer than anticipated, resulting in methodological implications. It is recommended that the intervention undergo further empirical inquiry, such as via a controlled trial. <http://spcare.bmj.com/content/early/2012/03/24/bmjspcare-2011-000131.abstract>
- *JOURNAL OF ADVANCE NURSING* | Online article – 21 March 2012 – '**Compassion fatigue in family caregivers: A Wilsonian concept analysis.**' The term 'compassion fatigue' is predominantly used with professional caregivers, such as nurses, doctors and social workers. Secondary traumatic stress, burnout, and other related terms are often cited in the literature in conjunction with compassion fatigue. Although compassion fatigue is linked to professional caregivers as a result of exposure to traumatizing events, minimal knowledge has been developed regarding its presence in family caregivers. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2648.2012.05985.x/abstract>
- *PALLIATIVE MEDICINE* | Online article – 26 March 2012 – '**Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study.**' The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based direct measure of carers' support needs in 14 domains. It is short but comprehensive in approach and thus suitable for both end-of-life care research and practice. Further work has been undertaken to test its psychometric properties. <http://pmj.sagepub.com/content/early/2012/03/23/0269216312440607.abstract>

### **The hospital environment for end of life care of older adults and their families: An integrative review**

*JOURNAL OF ADVANCE NURSING*, 2012;68(5):981-993. This article is a report of an integrative review to identify key elements of the physical hospital environment for end of life care of older adults and their families as reported by patients, relatives, staff and policy makers. Four themes were identified: privacy as needed; proximity (physically and emotionally) to loved ones, home and nature; satisfaction with the physical environment; and deficiencies in physical environment. Little evidence exists about physical hospital environments for end of life care of older adults and their families. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2648.2011.05900.x/abstract>

### **Using a LISTSERV™ to develop a community of practice in end-of-life, hospice, and palliative care social work**

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2012;8(1):77-101. The article discusses the concept of a technology supported 'Community of Practice.' Using content analysis, the article shows empirically how this electronic discussion group has contributed to the growth and expansion of a 'Community...' dedicated to improving palliative and end-of-life care among social workers. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2011.652857>

### **Information standard to close the communication gaps in end of life care**

NATIONAL END OF LIFE CARE PROGRAMME (U.K.) | Online posting – 20 March 2012 – The 'End of Life Care Co-Ordination: Core Content Information Standard' sets out and describes a core dataset of key information which is required to support the provision of safe and high quality care. It will ensure consistent recording of information by health and social care agencies and, with the consent of the individual, support safe and effective management and sharing of information. <http://www.endoflifecareforadults.nhs.uk/strategy/strategy/coordination-of-care/end-of-life-care-information-standard>

### **Cultural considerations in planning palliative and end of life care**

*PALLIATIVE MEDICINE*, 2012;26(3):195-196. Efforts to extend quality end-of-life care are underway in many countries, but are often under-resourced and lack coverage. Moreover, we still have limited agreement on just how these efforts might be more successful. There are examples from many societies of the apparent failure to care for older people effectively and adequately as they face death: at home, in hospitals, in care homes, prisons and other institutional settings. As the effects of population ageing are felt and as the incidence and prevalence of dementia increase, these challenges will grow. There are also special requirements arising from the pandemic of AIDS-related deaths and from increasing mortality associated with cancer in the developing world. Recently there has been debate about whether palliative care can or should be the answer to good end-of-life care in all contexts. <http://pmj.sagepub.com/content/26/3/195.extract>

### **Guidelines for nursing homes delivering end-of-life care to residents with dementia across the island of Ireland**

*QUALITY IN AGEING & OLDER ADULTS*, 2012;13(1):60-70. Findings [of this study] showed that the end of life care delivered was deemed by most elderly spouses to be of high quality, with person centred, individual, kind, professional care highly valued. Areas of dissatisfaction noted included poor communication, lack of involvement in key decision making, and poor symptoms control. Based on the study's findings, guidelines for the delivery of quality care in long stay residential institutions were developed in consultation with eight health service professionals. The authors hope these guidelines will contribute to improvements in the care of people with dementia at end of life and will form the basis for the future development of policy, practices and procedures. <http://www.emeraldinsight.com/journals.htm?articleid=17021848&show=abstract>

Cont.

From Media Watch, 6 February 2012:

- *AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS* | Online article – 31 January 2012 – **'Palliative care for advanced dementia: A pilot project in two nursing homes.'** <http://aja.sagepub.com/content/early/2012/01/04/1533317511432732.abstract>

### **Assisted (or facilitated) death**

Representative sample of recent articles, etc:

- *SCOTTISH UNIVERSITIES MEDICAL JOURNAL*, 2012;1(1):6-13. **'Licensed to kill – the impact of legalising euthanasia and physician assisted suicide on the training of U.K. medical students.'** There have been a number of attempts to legalise euthanasia and physician assisted suicide (PAS) in the U.K. over the past decade. The potential impact of legalising euthanasia and PAS in the U.K. on the training of medical students, the next generation of doctors, is examined in this discussion paper. <http://sumj.dundee.ac.uk/data/uploads/volume1/SUMJVVol1-p6-13.pdf>

From Media Watch, 16 January 2012:

- *AUSTRALIAN & NEW ZEALAND JOURNAL OF PSYCHIATRY*, 2012;46(2):87-91. **'What should we tell medical students and residents about euthanasia and assisted suicide?'** There are a lot of clinical and moral questions related to euthanasia and assisted suicide. In good teaching, we should help our trainees to identify these questions. We want medical trainees to understand that euthanasia and assisted suicide are a rejection of the importance and value of human life. Helping someone die ... violates the sanctity of life. <http://anp.sagepub.com/content/46/2/87.short>
- *THE PERMANENTE JOURNAL*, 2011;14(4):79-84. **'Physician-assisted suicide and euthanasia: Can you even imagine teaching medical students how to end their patients' lives?'** The peer-reviewed literature includes numerous well-informed opinions on the topics of euthanasia and physician-assisted suicide. However, there is a paucity of commentary on the interface of these issues with medical education. <http://www.thepermanentejournal.org/files/Fall2011/Suicide.pdf>

### **Worth Repeating**

#### **The "moment of death"**

*OMEGA – JOURNAL OF DEATH & DYING*, 2007;55(3):219-236. The "moment of death," once a dominant concept in preparing for a "good death," has been eclipsed by a focus on the wider concept of the "dying trajectory." However, findings from interviews with twenty-five bereaved individuals suggest that dying loved ones' final moments may still be experienced as highly significant in their own right. In some accounts the dying individual's final moments did not feature or made little impression, either because the survivor was not present, or there was no obviously definable moment, or because other, usually medical factors, such as whether to resuscitate the person, took precedence. However, in six cases such moments were constructed as profound, special, and memorable occasions. These constructions are explored in relation to achieving a good death, the dying trajectory as a whole, and making sense of the bereavement experience. Their implications for sociological theories of identity and embodiment are also considered. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,4,5;journal,38,255;linkingpublicationresults,1:300329,1>

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