## Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in hospice and palliative care, and in the quality of end-of-life care in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

## 5 January 2015 Edition | Issue #391



Compilation of Media Watch 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to <u>Specialist Publications</u> and 'Adolescent end-of-life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer' (p.8), in *Pediatric Blood & Cancer*.

## **Canada**

### We are camouflaging morbidity in clichés: It's time to talk about death

THE GLOBE & MAIL | Online – 1 January 2015 – Instead of dying, people "breathe their last" or "pass away" – most of them peacefully, often after a heroic struggle. Some of them just pass and they do it unexpectedly, which always reminds me of flatulence. At a time when the inevitability of death – our parents, ourselves – confronts us as never before, we are camouflaging morbidity in clichés. We rarely speak directly to mourners of the death of a loved one, especially by name or relationship. Rather, we mumble the generic (and anonymous) chestnut: "I'm sorry for your loss," as though a car has been stolen. The deceased is no longer "survived by" next of kin; instead he or she "leaves" spouses, siblings and offspring behind like objects forgotten in a storage locker at a bus station. Death today is like sex was for the Victorians. We know it occurs, we may even feel a prurient pleasure in hearing gruesome details, but most of us don't want to talk about the prospect of our own deaths or of those ahead of us in the trenches – and certainly not in public. http://www.theglobeandmail.com/life/health-and-fitness/health/lets-talk-about-death/article22266585/

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

CTV NEWS | Online – 31 December 2014 – 'New Year, new laws: Everything you need to know about this year's big bills.' The issue of giving Canadians the right to a physician-assisted suicide will play out both on the national and provincial stages in 2015. The Supreme Court is currently considering whether Criminal Code provisions against assisted suicide violate the Charter of Rights, and is expected to issue a ruling sometime before the year is out. Meanwhile, a new bill to legalize physician-assisted suicide has been introduced in the Senate, and could be referred to the House of Commons sometime in the spring. The bill's sponsors, ... say it will pave the way for the provinces to change their laws. Quebec already has a jump on the matter. In June, the National Assembly passed Bill 52, a comprehensive bill that deals with end-of-life care. [Scroll down to 'Right-to-Die.'] <a href="https://www.ctvnews.ca/politics/new-year-new-laws-everything-you-need-to-know-about-this-year-s-big-bills-1.2158537">https://www.ctvnews.ca/politics/new-year-new-laws-everything-you-need-to-know-about-this-year-s-big-bills-1.2158537</a>

## U.S.A.

### Partnership gives hospice care to homeless

CALIFORNIA | U-T San Diego - 2 January 2015 - [Kyla] Winters initiated Alpha's Hospice for The Homeless program in 2007-2009, but took a respite while dealing with her own near-death encounter with bacterial meningitis. Winters has returned to the cause of securing end of life care for homeless hospice clients, finding permanent housing for them, and soliciting partnerships with hospice care givers like Silverado San Diego. "These people qualify for hospice but you can't provide hospice for someone that's on the street, or under a bridge or in a bush," said Bob McElroy, president of the Alpha Project. "And that's what makes our partnership so unique, is that we find a place for people to stay. We're doing the best we can piecemeal, scattering people around when we can afford to provide rental subsidy for them," McElroy added, "but the ideal situation would be a place where we can have all the folks from all over the county that are facing these end of life issues, in one place that belongs to them." According to the Regional Task Force on the Homeless which conducts the annual Point in Time Count, on 23 January 2014 volunteers identified 8,506 homeless persons living in San Diego County, just less than half of whom (3,985) were unsheltered, living in a place not meant for human habitation. Over 13% of those were staying in emergency shelters and 37% in transitional housing programs. Figures from the San Diego County Medical Examiner's office put the number of homeless who died in San Diego last year at 63, with ages ranging from the late 20s to mid-70s. Causes of death include heart attacks, suicide, pneumonia-related illnesses, drug overdoses, accidental, seizures, fights and murder. http://www.utsandiego.com/news/2014/dec/31/homeless-hospice-death-dignity-Alpha-Project/

**N.B.** Several articles on end-of-life care for the homeless are noted in Media Watch, 3 February 2014, #343 (p.4). In the U.K., Marie Curie Cancer, with St. Mungo's Broadway, published 'Homelessness and End-of-Life Care.' <a href="http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf">http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf</a> [Noted in Media Watch, 20 May 2013, #306 (p.7)]. The Summer 2014 issue of *European Network of Homeless Health Worker*, which includes an article on homelessness, ageing and dying (p.7) is available at: <a href="http://www.sophie-project.eu/pdf/ENHW">http://www.sophie-project.eu/pdf/ENHW</a> 2014.pdf

#### When hospices mistreat the dying, they almost never get punished

THE HUFFINGTON POST | Online - 30 December 2014 - More dying Americans than ever now spend their last days in the care of a hospice, a service that offers a gentle alternative to a hospital setting. Hospice providers give comfort to the terminally ill, often in their homes. The promise is of a dignified death, surrounded by loved ones. But when a hospice fails in this mission - for one, by putting patients in physical danger - it almost always escapes sanctions. The federal government rarely punishes hospices that violate its health and safety rules, an examination by The Huffington Post reveals. In June, the Post found that hundreds of hospices had gone six years or more without a government agent conducting an inspection to make sure they were following Medicare's rules. Now, the new analysis shows that when inspections do occur and problems are identified, government inspectors are almost always satisfied with hospice promises that they'll reform. Medicare's federal regulator has punished a hospice just 16 times in the last decade, despite carrying out 15,000 inspections and identifying more than 31,000 violations. In each instance, the regulator terminated the hospice's license, the only sanction available under federal law. Because Medicare provides about 90% of funding for hospices, losing a license essentially forces a hospice to close down. http://projects.huffingtonpost.com/hospice-inc/top-offendinghospices-rarely-punished

1. 'How dying became a multibillion-dollar industry,' *The Huffington Post*, 19 June 2014. [Noted in Media Watch, 23 June 2014, #363 (p.2)] http://projects.huffingtonpost.com/hospice-inc

Cont.

#### Of related interest:

- NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION (NHPCO) | Online 27 December 2014 'National Hospice & Palliative Care Organization responds to latest Washington Post article.' In an article ... in ... [the] ... Washington Post ... examination of federal hospice cost report data points out differences among provider types. It may be inferred that tax status influences the quality of care a hospice provider delivers to patients and their families. The NHPCO is concerned that this article ... may confuse the public seeking care at the end of life. Assessing quality is not as simple as identifying whether a hospice provider is a non-profit or for-profit organization or looking at a single statistic. <a href="http://www.nhpco.org/press-room/press-releases/response-washington-post-article">http://www.nhpco.org/press-room/press-releases/response-washington-post-article</a>
  - 'Dying and profits: The evolution of hospice,' The Washington Post, 26 December 2014. Analysis of hundreds of thousands of hospice records indicates for-profit companies transformed a movement once dominated by community and religious organizations into a \$17 billion industry. [Noted in Media Watch, 29 December 2014, #390 (p.3)] <a href="https://www.washingtonpost.com/business/economy/2014/12/26/a7d90438-692f-11e4-b053-65cea7903f2e\_story.html">https://www.washingtonpost.com/business/economy/2014/12/26/a7d90438-692f-11e4-b053-65cea7903f2e\_story.html</a>

## Hospice: Are we prolonging life or prolonging death?

ILLINOIS | The Daily Herald (Chicago) - 28 December 2014 - The doctor floated through the intensive care unit ... moving from room to room, scanning one chart and then another, often frowning. Unlike TV dramas, where the victims of car crashes and gun shots populate the ICU, this one at Sentara Norfolk General in Virginia, as in others in the U.S., is more often filled with the wreckage of chronic disease and old age. Of 10 patients [Dr.] Paul Marik saw that morning, five had end-stage kidney disease, three had chronic respiratory ailments, some had advanced dementia. Some were breathing by virtue of machines; others had feeding tubes; a couple were in wrist restraints to prevent them from pulling off the equipment. For a man at a highly rated hospital surrounded by the technology of medical miracles, Marik sounded a note of striking skepticism: Patients too often suffer in vain attempts to prolong life, he said, because of

the mandate to "do everything" for patients. <a href="http://www.dailyherald.com/article/20141228">http://www.dailyherald.com/article/20141228</a> /business/141229640/

#### Extract from The Daily Herald article

Critics of U.S. health care have long marshaled evidence against the overuse of aggressive end-of-life care, but the idea that many Americans are dying badly – subjected to desperate treatments in ways that are not only expensive but painful and medically futile – has gained currency of late.

### **Specialist Publications**

'Training the next generation of doctors in palliative care is the key to the new era of value-based care' (p.5), in *Academic Medicine*.

#### 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: <a href="http://www.ipcrc.net/barry-r-ashpole.php">http://www.ipcrc.net/barry-r-ashpole.php</a>

## International

#### Elder care in England

### Government promises crackdown on "shocking" care homes

U.K. (England) | *The Telegraph* – 27 December 2014 – Nursing home owners who offer "shocking standards" of care will be rooted out and prosecuted, a senior government minister has pledged. Norman Lamb, the health minister, said there must be "no hiding place" for care homes that fail to treat residents with kindness and respect. The Government is introducing a series of measures next year that will give the Care Quality Commission the regulator, greater powers over failing services. These would ensure that: when care home companies fall short of standards "in a serious way" that leads to suffering, the company and "culpable directors" can be prosecuted; all care workers will be required to undergo training under a new care certificate scheme from next year, which Mr. Lamb described as "pretty close to compulsory minimum training standards"; directors of care homes will be subject to a "fit and proper person test" in an attempt to drive out those responsible for the worst scandals. He warned local authorities, which commission care services, must be held to account, although he stopped short of endorsing *The Telegraph*'s call for the Commission to be able to inspect local authorities to check how they organise services. <a href="http://www.telegraph.co.uk/health/healthnews/11314669/Government-promises-crackdown-on-shocking-care-homes.html">http://www.telegraph.co.uk/health/healthnews/11314669/Government-promises-crackdown-on-shocking-care-homes.html</a>

N.B. Care Quality Commission's care homes web page: http://www.cqc.org.uk/content/care-homes

#### Of related interest:

- U.K. (England) | The Express 29 December 2014 'Most elderly people "to lose out on care costs cap" because they won't live long enough.' As many as 90% of those who go into a residential home will die before they reach the cap limit of £72,000 set to be introduced in April 2016. The warning comes in analysis by the union for care staff, which found only a one in 10 chance that an elderly resident in a care home in England would reach the limit. <a href="http://www.express.co.uk/news/uk/549147/Elderly-to-lose-out-on-care-costs-cap-because-they-won-t-live-long-enough">http://www.express.co.uk/news/uk/549147/Elderly-to-lose-out-on-care-costs-cap-because-they-won-t-live-long-enough</a>
- U.K. | The Guardian 28 December 2014 'Social policies are lagging way behind our changing lives.' At the heart of Atul Gawande's last Reith lecture [in the BBC radio series] was an image upon which many of us would prefer not to dwell: institutionalised older people living out the ends of their lives in residential homes all over the world, ranging from the luxurious to the Dickensian. Be they for the rich or poor, Gawande argued that too often they are places where physical needs are catered for with little consideration for the fulfilment, flourishing and wellbeing of the people who live within their walls; a consequence of medicine, with its focus on how to stretch lifespans ever further, running far ahead of social policy. http://www.theguardian.com/commentisfree/2014/dec/28/politics-failing-to-find-solutions-forchanging-lives

N.B. Atul Gawande's Reith lectures: <a href="http://www.bbc.co.uk/search?q=Atul%20Gawande">http://www.bbc.co.uk/search?q=Atul%20Gawande</a>

# Updated 5 January 2015

#### **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.9.

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

## Training the next generation of doctors in palliative care is the key to the new era of value-based care

ACADEMIC MEDICINE | Online – 30 December 2014 – Although it includes hospice, palliative care [PC] is also the long-term coordinated care of the chronically ill, which is delivered at a cost savings. Why does it matter that the average American understands what PC means? Because the evidence shows U.S. patients near the end of life are spending exorbitant amounts of money on health care they do not want and the country cannot afford. To better understand why PC is an important issue in the current debate about health care reform, the authors review landmark legal cases in the area of end-of-life care. They also discuss the role of PC in conversations in the current health care climate and conclude by emphasizing the importance of integrating PC into the standard medical curriculum. The authors predict that PC will be accepted in the U.S. as a muchneeded and desirable field of medicine. Getting there, however, will require a multifaceted approach including payment reform, encouraging an open conversation among the U.S. public and training physicians to offer the best possible care and guidance until a patient's last breath. http://journals.lww.com/academicmedicine/Abstract/publishahead/Training\_the\_Next\_Generation of Doctors\_in.98889.aspx

#### Of related interest:

■ ACADEMIC MEDICINE | Online – 30 December 2014 – 'Junior doctors' views of how their undergraduate clinical electives in palliative care influenced their current practice of medicine.' Findings [of this study] suggest junior doctors trained earlier in PC have enhanced competencies of professionalism, patient-centered medicine, psychosocial and spiritual aspects of PC, communication, teamwork, and self-awareness. Learning a palliative approach can help them make a difference in treating dying patients, but also in general patient care. <a href="http://journals.lww.com/academicmedicine/Abstract/publishahead/Junior Doctors Views of How\_Their\_Undergraduate.98886.aspx">http://journals.lww.com/academicmedicine/Abstract/publishahead/Junior Doctors Views of How\_Their\_Undergraduate.98886.aspx</a>

# Developing organizational guidelines for the prevention and management of suicide in clients and carers receiving palliative care in Australia

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 December 2014 – This article describes the process of developing a suicide guideline in palliative care. Little literature was available, but utilizing the partnership model, a working party consulted with each discipline regarding specific requirements. The working party experienced significant challenges in creating policy that would adequately cover the diverse needs of all members of the palliative care team, as it was recognized that all staff needed guidance. The final guideline incorporated specific action plans for each discipline; mandatory training for all staff was endorsed through a recognized suicide alertness training program; advanced training in suicide intervention skills for key clinical staff will be required; and a 'Rapid Plan Team' was recommended. This policy development has required significant work and the combined expertise of many disciplines. http://ajh.sagepub.com/content/early/2014/12/29/1049909114565659.abstract

#### 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. <a href="http://www.pcn-e.com/community/pg/file/owner/MediaWatch">http://www.pcn-e.com/community/pg/file/owner/MediaWatch</a>

## End-of-life care for people with cancer from ethnic minority groups: A systematic review

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 December 2014 – Twenty-five studies were included: 20 quantitative and five qualitative. All ... focused on the ethnic/racial minority groups of African Americans, Hispanics Americans, or Asian Americans. Key themes included EOL [end of life] decision making processes, family involvement, provider communication, religion and spirituality, and patient preferences. Hospice was the most studied EOL care, and was most used among Whites, followed by use among Hispanics, and least used by African and Asian Americans. African Americans perceived a greater need for hospice, yet more frequently had inadequate knowledge. African Americans preferred aggressive treatment, yet EOL care provided was often inconsistent with preferences. Hispanics and African Americans less often documented advance care plans, citing religious coping and spirituality as factors. http://ajh.sagepub.com/content/early/2014/12/29/1049909114565658.abstract

### An emerging concept: Peaceful letting go

ARCHIVES OF PSYCHIATRIC NURSING | Online – 27 December 2014 – The concept of peaceful letting go emerged to describe the emotional, transitional and decision making processes that family members experience in losing an older adult loved one with a life-limiting illness. As many older adult patients due to their extreme morbidity are unable to express their end of life preferences; families are faced with having to make difficult decisions regarding their loved ones' care... These decisions are often fraught with upheaval that takes a toll on the mental health of family members. http://www.psychiatricnursing.org/article/S0883-9417(14)00179-4/abstract

Noted in Media Watch, 19 November 2012, #280 (p.11):

SOCIAL SCIENCE & MEDICINE | Online – 15 November 2012 – 'The art of letting go: Referral to palliative care and its discontents.' While medical specialists are expected to ease their patients transitions to specialist palliative care if required, few have received formal training in such interpersonal complexities. The results [of this study] illustrate how this transitional realm can be embedded in emotions, relationships and the allure of potentially life-prolonging intervention. <a href="https://www.sciencedirect.com/science/article/pii/S0277953612007575?v=s5">https://www.sciencedirect.com/science/article/pii/S0277953612007575?v=s5</a>

## Quality of hospice care: Comparison between rural and urban residents

JOURNAL OF NURSING CARE QUALITY | Online – 26 December 2014 – Discrepancies between needed and received hospice care exist, especially in rural areas. Hospice care quality ratings for 743 rural and urban patients and their families were compared. Rural participants reported higher overall satisfaction with pain/symptom management. Regardless of geographic location, satisfaction was higher when patients were informed and emotionally supported. Findings support prior reports using retrospective rather than the authors' point-of care surveys. <a href="http://journals.lww.com/jncqjournal/Abstract/publishahead/Quality of Hospice Care Comparison\_Between\_Rural.99716.aspx">http://journals.lww.com/jncqjournal/Abstract/publishahead/Quality of Hospice Care Comparison\_Between\_Rural.99716.aspx</a>

Noted in Media Watch, 14 January 2013, #388 (p.13):

■ RURAL & REMOTE HEALTH | Online – 7 January 2013 – 'Comparing the experiences of rural and urban family caregivers of the terminally ill.' Previous work has identified consistent themes around end-of-life care, including caregiver burden in providing care, the importance of informal care networks and barriers imposed by geography. Despite these well-known barriers, few studies have explored the experience of palliative care in rural settings. Urban and rural caregivers reported similarly high levels of social support. Rural caregivers reported greater use of family physicians, emergency room visits and pharmacy services, while urban caregivers reported greater use of caregiver respite services. Results ... suggest that while there are commonalities to the caregiving experience regardless of setting, key differences also exist. <a href="http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250">http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250</a>

## Massage, music and art therapy in hospice: Results of a national survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 30 December 2014 – Twenty-nine percent of hospices reported employing an art, massage, or music therapist. Of those hospices, 74% employed a massage therapist, 53% a music therapist, and 22% an art therapist, and 42% expected the therapist to attend interdisciplinary staff meetings, indicating a significant role for these therapists on the patient's care team. Larger hospices compared with smaller hospices had significantly higher odds of employing a CAM [complementary and alternative medicine] therapist and for-profit hospices had lower odds of employing a CAM therapist compared with non-profit hospices. Forty-four percent of hospices in the Mountain/Pacific region reported employing a CAM therapist versus 17% in the South Central region. Less than one-third of U.S. hospices employ art, massage, or music therapists despite the benefits these services may provide to patients and families. http://www.ipsmjournal.com/article/S0885-3924(14)00942-7/abstract

# Curricular innovations for medical students in palliative and end-of-life care: A systematic review and assessment of study quality

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 December 2014 – Recent focus on palliative and end-of-life care has led medical schools worldwide to enhance their palliative care curricula. The sample described 48 curricula in 12 countries. Faculty were usually interdisciplinary. Palliative care topics included patient assessment, communication, pain and symptom management, psychosocial and spiritual needs, bioethics and the law, role in the health care system, interdisciplinary teamwork, and self-care. Thirty-nine articles included quantitative evaluation... Recent innovations in palliative care education for medical students represent varied settings, learner levels, instructors, educational modalities, and palliative care topics. Studies could be improved by integrating longitudinal curricula and longer-term outcomes; collaborating across institutions; using validated measures; and assessing higher-level outcomes including skills, behaviors, and impact on patient care. <a href="http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0270">http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0270</a>

Noted in Media Watch, 15 December 2014, #388 (p.15):

■ JOURNAL OF CANCER EDUCATION | Online – 9 December 2014 – 'Inadequacy of palliative training in the medical school curriculum.' This report examines the literature on palliative training in the current medical school curriculum. Physicians and medical students both report feeling that their training in end-of-life care and in palliative issues is lacking. The literature expresses concerns about the varied and non-uniform approach to palliative care training across medical schools. http://link.springer.com/article/10.1007/s13187-014-0762-3

N.B. Additional articles on palliative care in the medical school curriculum are noted in this issue of Media Watch.

#### The importance of elaborating criteria to select staff in palliative care

PALIAŢIA, 2015;8(1). Hiring staff in palliative care without taking into account certain specific selection criteria could have adverse consequences on the health of patients, relationships with other team members in an institution management and staff could not cope with a tense atmosphere at work, possibly getting sick. Professionals must have passion to care for patients in the terminal stage, to be sensitive to their suffering, behaviour and attitudes, values, thoughts and feelings, to have the ability to listen, to find solutions, to intervene, to provide the best care, to be open and flexible, to be able to work alone and in teams. Failure criteria for staff selection may affect the activity in palliative care, the health of the patients and the professionals, the management of the institution, and its image. Stressful situations may occur between team members, resulting in anxiety and conflict, from which it can result in complaints. It can be said that an improper employee is a risk factor for the institution offering palliative care and can generate more negative effects over time. <a href="http://www.paliatia.eu/new/2015/01/the-importance-of-elaborating-criteria-to-select-staff-in-palliative-care/">http://www.paliatia.eu/new/2015/01/the-importance-of-elaborating-criteria-to-select-staff-in-palliative-care/</a>

N.B. Romanian language article.

## Adolescent end-of-life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer

PEDIATRIC BLOOD & CANCER | Online – 24 December 2014 – Little is known about how well family members accurately represent adolescents when making EOL [end-of-life] decisions on their behalf. This study reports on surveys given to adolescents with cancer and their parents as part of a larger study facilitating advanced care discussions, as well as the results of a survey for health care providers. Seventeen adolescent/family dyads completed this survey. Seventy five percent of adolescents believed it was appropriate to discuss EOL decisions early and only 12% were not comfortable discussing death. Most preferred to be at home if dying. There were substantial areas of congruence between adolescents and their surrogates, but lower agreement on the importance of dying a natural death, dying at home and "wanting to know if I were dying." <a href="http://onlinelibrary.wiley.com/doi/10.1002/pbc.25358/abstract;jsessionid=4C5DE355E6EEF07FA5708EC6754C6B88.f02t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false">http://onlinelibrary.wiley.com/doi/10.1002/pbc.25358/abstract;jsessionid=4C5DE355E6EEF07FA5708EC6754C6B88.f02t04?deniedAccessCustomisedMessage=&userIsAuthenticated=false</a>

Noted in Media Watch, 29 September 2014, #377 (p.10):

■ JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS, 2014;12(7): 405-447. 'Factors influencing the provision of end-of-life care for adolescents and young adults with advanced cancer: A scoping review.' Cancer is the third leading cause of death in adolescents and young adults; little is known about how the end of life unfolds for those who die of the progressive disease. http://joannabriggslibrary.org/index.php/jbisrir/article/view/1622

Noted in Media Watch, 15 October 2012, #275 (p.3):

PEDIATRICS | Online – 8 October 2012 – 'Allowing adolescents and young adults to plan their end-of-life care.' [Study participants] want to be able to choose and record: 1) the kind of medical treatment they want and do not want; 2) how they would liked to be cared for: 3) information for their family and friends to know; and, 4) how they would like to be remembered. <a href="http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0663.abstract">http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0663.abstract</a>

#### **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.

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ SOCIAL SCIENCE & MEDICINE | Online – 29 December 2014 – 'Attitudes towards legalising physician provided euthanasia in Britain: The role of religion over time.' The authors use a nationally representative survey of public attitudes – the British Social Attitudes survey – to examine changes in attitudes to the legalisation of physician provided euthanasia over almost 30 years (1983-2012) and the role of religious beliefs and religiosity in attitudes over time. The support for legalization rose from around 76.95% in 1983 to 83.86% in 2012. This coincided with an increase in secularization exhibited in the survey: the percentage of people with no religious affiliation increasing from 31% to 45.4% and those who do not attend a religious institution increasing from 55.7% to 65.03%. The authors' study demonstrates an increase in the support of euthanasia legalisation in Britain in the last 30 years coincided with increased secularization. <a href="http://www.sciencedirect.com/science/article/pii/S0277953614008387">http://www.sciencedirect.com/science/article/pii/S0277953614008387</a>

#### **Media Watch Online**

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <a href="http://hospicecare.com/about-iahpc/newsletter/2014/12/media-watch/">http://hospicecare.com/about-iahpc/newsletter/2014/12/media-watch/</a>

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

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

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

#### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: http://aphn.org/category/media-watch/

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

#### Australia

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

#### Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <a href="http://hpcconnection.ca/general-resources/in-the-news/">http://hpcconnection.ca/general-resources/in-the-news/</a>

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

### Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <a href="http://www.eapcnet.eu/Themes/Organization/Links.aspx">http://www.eapcnet.eu/Themes/Organization/Links.aspx</a> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes

U.K. | Omega, the National Association for End-of-Life Care: <a href="http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESID=b623758904ba11300ff6522fd7fb9f0c">http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESID=b623758904ba11300ff6522fd7fb9f0c</a>

## **Worth Repeating**

# The allied health care professional's role in assisting medical decision making at the end of life

TOPICS IN LANGUAGE DISORDERS, 2012;32(2):119-136. This article provides an overview of the complex issues the practicing clinician needs to keep in mind when assisting clients with advance care planning. This service requires that clinicians step outside their roles as rehabilitation experts, a move that is supported by professional associations. The concepts of medical decision making and informed consent are discussed in the context of decisions made in advance of illness at the end of life. The professional needs also to be aware of the legalities of advance decision making, as laws and statutes differ between states/provinces. There are overarching pieces of legislation that inform local legal and policy issues; the impact of these is briefly addressed. Various forms of documenting advance care plans, as well as their strengths and weaknesses, are discussed. Decision models are introduced as a means of guiding the clinician to provide quality care. Means of offering practical assistance to the client, such as motivational interviewing, the careful selection of appropriate educational material, and prevention of undue influence on the patient are discussed. Finally, the role of the allied health care professional in advocating for the client during the implementation is addressed. Understanding how the advance

care plan should be implemented when a patient becomes incapable is essential when advocating for and protecting the rights of the patient. When a professional is prepared with the requisite understanding of all of the facets of advance care planning, he or she can become a strong ally for the patient and the family at this very important phase of life. <a href="http://journals.lww.com/topicsinlanguagedisorders/Abstract/2012/04000/The\_Allied\_Health\_Care\_Professional\_s\_Role\_in.4.aspx">http://journals.lww.com/topicsinlanguagedisorders/Abstract/2012/04000/The\_Allied\_Health\_Care\_Professional\_s\_Role\_in.4.aspx</a>

## Extract from *Topics in Language Disorders* article

Allied health care professionals, including speech-language pathologists and occupational therapists, can be instrumental in assisting their patients to make advance care plans, although their traditional job descriptions do not include this role. The allied health care professional is often in a trusted position, permitting insight into the values and beliefs of the patient and facilitating the depth of communication necessary when making difficult decisions. Professionals who work with clients at the end of life need to be aware of the many issues surrounding end-of-life decision making and the preparation of advance directives for care.

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