Media Watch...

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

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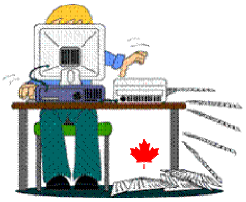


Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Flying blind: Sources of distress for family caregivers of palliative cancer patients managing pain at home' (p.10), in *Journal of Psychosocial Oncology*.

Canada

National Democratic Party presents bill to improve end-of-life care

SASKATCHEWAN | *The Regina-Leader Post* – 1 November 2013 – The New Democratic Party [NDP] called for a national framework to improve the quality of end-of-life care in Canada. Libby Davies, the NDP's health critic ... introduced a private member's bill in the House of Commons calling for a co-ordinated, national response to continuing care.[1,2] The bill was seconded by Charlie Angus, ethics critic and MP for Timmins-James Bay, who added a motion to establish a national strategy on palliative care. "We know many Canadians are falling through the cracks, we know there's not enough home care, long-term care or palliative care to meet the current demand in Canada," Davies said. Bill C-545, would have the minister of health establish an appointed advisory committee to meet at least four times per year. The committee would first review the current conditions of continuing care then come up with pan-Canadian standards to deliver continuing care. http://www.leaderpost.com/health/presents+bill+improve+life+care/9111548/story.html

1. Bill C-545, An Act Respecting the Provision of Continuing Care to Canadians: http://www.parl.gc.ca/content/hoc/Bills/412/Private/C-545/C-545_1/C-545_1.PDF
2. Motion to introduce Bill C-545: Hansard (Scroll down to 'Continuing Care for Canadians Act'): http://www.parl.gc.ca/HousePublications/Publication.aspx?Language=E&Mode=1&Parl=41&Ses=2&DocId=6279197#OOB-8116452

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

Hospice says inequality ... funding to blame for lack of local facility

BRITISH COLUMBIA | *The Courier-Islander* (Campbell River) – 30 October 2013 – Dying with dignity in Campbell River is worth 22¢ a head. That is what [Vancouver] Island Health (VIHA) pays towards the rights of Campbell River citizens to die in peace, free of pain, surrounded by their loved ones, in the setting of their choice. And for twenty two cents, that just is not going to happen. Iona Wharton, Campbell River Hospice Director of Programs & Services, and Judy Collis, Director of Operations, said that there is a significant disproportionately and inequality in the way hospices receive funding from VIHA. As a result, Campbell River Hospice Society cannot move forward to obtain a house for Hospice in order to provide the services Campbell River needs. According to their calculations, Wharton and Collis said that based on the $15,700 given to each of the nine hospice agencies south of [the provincial capital] Victoria every year, Campbell River Hospice has 22¢ for every person requiring end-of-life support or bereavement counselling. Campbell River is third out of those nine in service numbers, helping 1,516 this past year, just behind Nanaimo [Community Hospice] at 2,110 and Comox [Valley Hospice] at 1,907. http://www.canada.com/Hospice+says+inequality+VIHA+funding+blame+lack+local+facility/9099766/story.html

Of related interest:

- BRITISH COLUMBIA | *The Cowichan News Leader* (Duncan) – 29 October 2013 – **'Proposal to have hospice operations funded by local government rejected...'** Cowichan Valley Hospice and the Cowichan Valley Regional District went all in, asking the provincial government if it would change legislation to fund both local hospice care's capital and operational costs. It didn't get the support it wanted from local government. A motion recently brought to the UBCM [Union of B.C. Municipalities] conference table was passed but stripped of the operational funding portion. http://www.cowichannewsleader.com/news/229599441.html

Noted in Media Watch, 7 October 2013, #326 (p.1):

- BRITISH COLUMBIA | *The Nanaimo Daily News* – 4 October 2013 – **'Provincial committee told funding often inadequate.'** Wendy Pratt, Nanaimo Community Hospice executive director, spoke [to a Select Standing Committee on Finance & Government Services] for stable, annualized funding. Where Victoria Hospice Society, which derives half its budget of more than $7million from the province, outside Victoria only $140,000 is available for the other hospices. http://www.canada.com/Provincial+committee+told+funding+often+inadequate/8998321/story.html

Noted in Media Watch, 1 April 2013, #299 (p.2):

- BRITISH COLUMBIA | *The Comox Valley Record* (Courtenay) – 27 March 2013 – **'Comox Valley wonders where its end-of-life funding is.'** Where's the funding for end-of-life care in the Comox Valley? The Comox Valley Hospice Society has been asking this question for years, but after the Health Ministry's announcement this week of millions for hospice care in the Lower Mainland, the society is asking the question with renewed vigour. http://www.comoxvalleyrecord.com/news/200335711.html

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Calgary Herald* – 3 November 2013 – **'Tories tackle hot-button issues ... on last day of summit.'** One issue that did provoke serious debate [at Conservative Party's three-day convention] before passing was a resolution opposing euthanasia and assisted suicide. Saskatoon-Humboldt delegate Cecilia Forsyth said legal euthanasia would give doctors "the right to directly and intentionally cause your death." There was opposition from the floor, with one delegate urging party members "to walk a mile in the shoes of a dying person." http://www.calgaryherald.com/news/politics/Tory+delegates+pass+resolution+opposing+assisted+suicide/9117607/story.html

Cont.

Specialist Publications

'Physician-assisted suicide goes back to court in Canada,' (p.15) in *The Jurist*.

- BRITISH COLUMBIA | *The National Post* – 29 October 2013 – **'B.C. group hopes to take assisted suicide fight to Supreme Court for first time in 20 years.'** The British Columbia Civil Liberties Association filed for a Supreme Court hearing of *Carter v. Canada*, the landmark B.C. case that legalized assisted suicide in June 2012 before it was overturned by the B.C. Court of Appeal. http://news.nationalpost.com/2013/10/29/b-c-group-hopes-to-take-assisted-suicide-fight-to-supreme-court-for-first-time-in-20-years/

  Noted in Media Watch, 14 October 2013, #327 (p.2):

  - BRITISH COLUMBIA | CBC News (Vancouver) – 10 October 2013 – **'Doctor-assisted suicide ban upheld in B.C.'** The B.C. Court of Appeal, in a split decision, has affirmed the law against assisted suicide, in a controversial and historic right-to-die case. Last year, ALS patient Gloria Taylor of Kelowna won a landmark ruling when a B.C. Supreme Court judge struck down Canada's law that made doctor-assisted suicide illegal. Regardless of [this latest] ruling, many observers expect the case will end up at the Supreme Court of Canada. http://www.cbc.ca/news/canada/british-columbia/doctor-assisted-suicide-ban-upheld-in-b-c-1.1958888

- QUEBEC | *The Globe & Mail* – 29 October 2013 – **'Quebec's end-of-life care bill clears second reading.'** The legislation on "end of life care" tabled last June that includes a provision for medically assisted suicide – the first of its kind in Canada – was adopted in second reading in a free vote by members of the Quebec National Assembly [Assemblée nationale du Québec]. This was a clear indication that a majority of members support the legislation, paving the way for final adoption ... after a clause-by-clause review during committee hearings this fall. http://www.theglobeandmail.com/news/politics/quebecs-end-of-life-care-bill-clears-second-reading/article15149845/

- CBC NEWS | Online – 25 October 2013 – **'Support for assisted suicide at an all-time high in Canada.'** A recent poll reveals the level of support for assisted suicide among Canadians is slightly higher than it was at the time of the Sue Rodriguez Supreme Court case in 1993.[1,2] There are some shifts in where support is strongest – and weakest. Support ranges from a low of 59% among those without a high school education to a high of 85% among Bloc Quebecois supporters. http://www.cbc.ca/news2/interactives/assisted-suicide/

  1. 'Canadian public opinion on assisted suicide,' The Environics Institute, October 2013. Includes data going back 20 years. http://www.environicsinstitute.org/news-events/news-events/canadian-public-opinion-on-assisted-suicide

  2. 'Sue Rodriguez and the Right-To-Die Debate,' from the CBC Digital Archives: http://www.cbc.ca/archives/categories/politics/rights-freedoms/sue-rodriguez-and-the-right-to-die-debate/topic-sue-rodriguez-and-the-right-to-die-debate.html

  N.B. 'Last Right: Assisted Suicide in Canada,' the first in a scheduled four-part series on the CBC's prime time news program, The National, was broadcast 28 October 2013. The second and third episodes are scheduled for broadcast 4 and 13 November 2013, respectively. http://www.cbc.ca/player/News/TV+Shows/The+National/ID/2414736522/

U.S.A.

Hospice care in America: Facts and figures

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – Accessed 31 October 2013 – The organization's *Facts & Figures: Hospice Care in America, 2013 Edition* provides an overview of trends in the growth, delivery and quality of hospice care across the country with specific information on hospice patient characteristics (e.g., gender, age, ethnicity, race, primary diagnosis, and length of service); hospice provider characteristics (e.g., total patients served, organizational type, size, and tax status; location and level of care; and, role of paid and volunteer staff. http://www.nhpco.org/sites/default/files/public/Statistics_Research/2013_Facts_Figures.pdf

'Cost of Dying' reporting, advocacy wins Journalist of the Year Award for *Mercury News* writer

CALIFORNIA | *The Contra Costa Times* (Walnut Creek) – 28 October 2013 – *San Jose Mercury News* staff writer Lisa M. Krieger has been named Journalist of the Year by the Society of Professional Journalists [North California Chapter] for her 'Cost of Dying' series and her "dedication to helping the public understand critical decisions about end-of-life care." The Society noted Krieger's work, including print stories, interactive graphics, videos, online chats and community forums, "continue to help the public understand the complex and emotionally fraught choices dying individuals and their caretakers must often make." http://www.contracostatimes.com/bay-area-news/ci_24405037/cost-dying-reporting-advocacy-wins-journalist-year-award

Noted in Media Watch, 4 March 2013, #295 (p.2):

- CALIFORNIA | *San Jose Mercury-News* – 26 February 2013 – **'Cost of Dying' series wins national health care journalism award.'** Two Bay Area News Group journalists have won a first-place national award for their year-long series 'Cost of Dying.' Lisa Krieger and Dai Sugano won the top prize in the consumer/feature category of the Association of Health Care Journalists contest for newspapers with circulations above 100,000. Their work detailing how harsh the end-of-life experience can be and gentler ways to die also received honorable mention in the health policy category. http://www.mercurynews.com/health/ci_22671926/cost-dying-series-wins-national-health-care-journalism

N.B. 'Cost of Dying' series: www.mercurynews.com/cost-of-dying. [Noted in Media Watch, 31 December 2012, #286 (p.1)]

How TV does, and doesn't, deal with death

TIME MAGAZINE | Online – 24 October 2013 – How do you recommend a TV series that's well-made, thought-provoking, deeply moving – and that most of your readers, with good reason, will not want to watch? That was my conundrum reviewing 'Time of Death,' a six-part documentary beginning 1 November on Showtime. The series, in mostly unadorned *vérité* style, follows patients with terminal illnesses through treatment, hospice care, up to and beyond the moment of death. http://entertainment.time.com/2013/10/24/dead-tree-alert-how-tv-does-and-doesnt-deal-with-death/

N.B. 'Time of Death' website: http://www.sho.com/sho/time-of-death/about

Nursing homes may not establish blanket no-CPR policies

MCKNIGHT'S LONG-TERM CARE NEWS & ASSISTED LIVING | Online – 28 October 2013 – Nursing homes will face survey citations for facility-wide policies that prohibit cardiopulmonary resuscitation [CPR] for residents, according to a recent Centers for Medicare & Medicaid Services memorandum. Research has shown that CPR is not very effective in the elderly nursing home population, and some facilities have put in place general no-CPR policies, the memo states. However, this does not comply with federal regulations that guarantee the right of residents to formulate advance directives. http://www.mcknights.com/cms-nursing-homes-may-not-establish-blanket-no-cpr-policies/article/318188/

Specialist Publications

'Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the U.S.: Perspectives of care managers on challenges and recommendations' (p.8), in *Health & Social Care in the Community.*

'Joining together to improve outcomes: Integrating specialty palliative care into the care of patients with cancer' (p.9), in *Journal of National Comprehensive Cancer Network.*

'American Academy of Pediatrics Policy Statement: Pediatric Palliative Care and Hospice Care Commitments, Guidelines and Recommendations' (p.13), in *Pediatrics*.

International

Funding end-of-life care in the U.K.

Increasing numbers of hospices using social media, reveals survey

U.K. | *CHARITY DIGITAL NEWS* – 1 November 2013 – Access Group has published the results of its survey into how U.K. hospice staff use social and digital tools for fundraising and communications.[1] The survey found that the amount of hospices which allowed donors to manage their accounts online had doubled, but the overall figure remained low, with just 20% of respondents allowing people to manage and maintain their accounts online – potentially missing a huge fundraising opportunity. http://www.charitydigitalnews.co.uk/2013/11/01/increasing-numbers-of-hospices-using-social-media-reveals-survey/

1. Access Group survey results: http://www.theaccessgroup.com/downloads--resources/email/hospiseconf-infographic.aspx

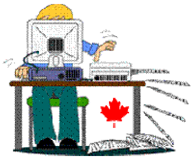
U.K. Supreme Court ruling

David James death: Doctors "right" to withhold treatment

U.K. | BBC News – 31 October 2013 – Judges were right to allow doctors to withhold treatment from a "gravely ill" guitarist, the Supreme Court has ruled. David James, 68, of Liverpool, died in 2012, days after doctors successfully argued in court that stopping treatment was in his best interests. In upholding the ruling, Supreme Court judge Lady Hale said the Court of Appeal had "reached the right result but for the wrong reasons." She said: "The trial judge applied the right principles and reached the conclusion which he was entitled to reach on the evidence before him. But by the time the case had reached the Court of Appeal, there had been a dramatic deterioration in Mr. James' condition such that the Court of Appeal was entitled to grant the declaration that it did. Technically therefore, the appeal is dismissed. But the family have won the argument of principle." The Supreme Court also emphasised the need to take into account not just the medical factors in the case, but "the patient's welfare in the widest sense," with great weight to be given to the patient's family life. http://www.bbc.co.uk/news/uk-england-merseyside-24741844

Of related interest:

- U.K. (SCOTLAND) | STV News – 28 October 2013 – **'Staff did not follow policy when deciding not to resuscitate patients.'** Hospital staff has been told they must consistently comply with the national policy when decisions are made not to resuscitate patients. Inspectors who visited St John's Hospital in Livingston, West Lothian, found there were cases where decisions were made in which the appropriate documentation and national policy was not followed. http://news.stv.tv/scotland/245923-st-johns-staff-did-not-follow-policy-about-resuscitating-patients/



Barry R. Ashpole

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

Australian Capital Territory plan to meet growing demand for palliative care

AUSTRALIA (AUSTRALIAN CAPITAL TERRITORY) | ABC News (Canberra) – 28 October 2013 – The government has unveiled a plan to deal with a predicted surge in demand for palliative care services in Canberra over the next five years.[1] The plan predicts demand for palliative services at Canberra and Calvary hospitals will rise by nearly 3.5% per year due to population growth, aging and increased incidence of cancer ... [and] ... outlines a strategy to meet this growing demand and raise community awareness about end-of-life care services. It includes improving access to palliative care by children, people with disabilities, and people from culturally diverse backgrounds. The plan aims for more seamless transitions for patients between care venues and more coordinated care. There will be a funding boost to improve the workforce and more dedicated palliative care beds, from 19 to 25 in 2016-2017, and then to 30 beds in 2021-2022. Chief Minister Katy Gallagher ruled out building a new hospice in the capital. http://www.abc.net.au/news/2013-10-28/act-government-unveils-palliative-care-plan/5048952

Specialist Publications

'Australian survey of current practice and guideline use in adult cancer pain assessment and management: Perspectives of palliative care physicians' (p.10), in *Journal of Palliative Medicine.*

1. *Australian Capital Territory Palliative Care Services Plan*, 2013-2017. http://health.act.gov.au/c/health?a=dlpubpoldoc&document=2867

Noted in Media Watch, 28 October 2013, #329 (p.3):

- AUSTRALIA (AUSTRALIAN CAPITAL TERRITORY) | *The Canberra Times* – 28 October 2013 – **'Palliative care demand set to soar.'** The government predicts a surge in demand for palliative care services in the territory within the next 10 years. The government will publish a plan to cope with the rising number of Canberrans who will require end-of-life care by the year 2022. http://www.canberratimes.com.au/act-news/palliative-care-demand-set-to-soar-20131027-2wa36.html

Of related interest:

- AUSTRALIA (NEW SOUTH WALES) | *Australian Ageing Agenda* – 1 November 2013 – **'Push to embed specialist palliative care in aged care.'** All residential aged care facilities should have access to specialist palliative care services, Palliative Care New South Wales [NSW] is recommending following a forum at Sydney's Parliament House. The forum discussed how to improve palliative care services in NSW following the state government's announcement for $35 million in funding for community-based palliative care to close some current gaps.[1] http://www.australianageingagenda.com.au/2013/11/01/push-to-embed-specialist-palliative-care-in-aged-care/

    1. '$35 million for New South Wales community-based palliative care,' *Australian Ageing Agenda*, 12 September 2013. http://www.australianageingagenda.com.au/2013/09/12/35-million-for-nsw-community-based-palliative-care/

Quotable Quotes

When the time comes to die, make sure that all you have to do is die! in *Journals of Jim Elliot.* [Grand Rapids, MI: Revell, 2002]

Cancer patients in Lancashire denied wish to die at home

U.K. (ENGLAND) | ITV News – 28 October 2013 – Almost three quarters of cancer patients in England who die in hospital beds wanted to die at home – an estimated 890 people in Lancashire each year, according to figures released by Macmillan Cancer Support.[1] Existing Macmillan research reveals the vast majority of health professionals (96%) agree access to social care services is crucial for keeping people out of hospital. However, two years after the Palliative Care Funding Review recommended social care should be free for those at the end of life thousands of cancer patients are still spending their last remaining days and hours on a hospital ward.[2] 'Time to Choose' sets out new recommendations for improving choice at end of life for cancer patients. It calls on the Government to make social care free for everyone in the last weeks of life before the end of this Parliament in 2015. http://www.itv.com/news/granada/2013-10-28/cancer-patients-in-lancashire-denied-wish-to-die-at-home/

Extract from
Time to Choose...

Delivering choice should always be about giving people the support to have a "good death," no matter where they wish to die. Therefore, understanding experiences of care at the end of life is key to delivering meaningful choice. As a first step, there is a pressing need to explore how the experiences of people at the end of life can be captured and used to monitor and improve outcomes. Although the VOICES survey of bereaved relatives is an extremely valuable source of information,[3] the lack of nationally collected feedback from people at the end of life needs to be addressed.

1. *Time to Choose: Making Choice at the End of Life a Reality*, Macmillan Cancer Support, October 2013. http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Endoflife/TimeToChoose.pdf

2. *Funding the Right Care & Support for Everyone: Final Report of the Palliative Care Funding Review*, July 2011. [Noted in Media Watch, 4 July 2011, #208 (p.4)] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

3. 'National Bereavement Survey, 2011,' Office for National Statistics, July 2012. [Noted in Media Watch, July 2012, #261 (p.4)] http://www.ons.gov.uk/ons/dcp171778_269914.pdf

National perspective on *Time to Choose*:

- U.K. (ENGLAND) | *The Guardian* – 28 October 2013 – **'36,000 cancer patients denied their last wish to die at home.'** Macmillan Cancer Support calls on the government to make social care free for everyone at the end of life. http://www.theguardian.com/living-with-cancer-macmillan-partner-zone/cancer-patients-denied-wishes-die

Noted in Media Watch, 28 October 2013, #329 (p.3):

- U.K. (ENGLAND) | *The Nottingham Post* – 25 October 2013 – **'Cancer group anger on home care issue.'** Hundreds of people in Nottingham are dying in hospital beds when they would prefer to pass away at home. Macmillan Cancer Support has unearthed figures which suggest 770 people who died of cancer in a hospital bed would have preferred to be at home. http://www.nottinghampost.com/Cancer-group-anger-home-care-issue/story-19987691-detail/story.html

Of related interest:

- U.K. (ENGLAND) | National End of Life Care Intelligence Network – 4 November 2013 – **'New report from Public Health England shows improvements in end of life care.'** The proportion of people dying at home or in care homes increased from 38% in 2008 to 44% in 2012, according to a new report from Public Health England's National End of Life Care Intelligence Network. However, the report also found there were large variations in the proportion of deaths in hospital between 2009 to 2011. http://www.endoflifecare-intelligence.org.uk/news/

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

Of the soul and suffering: Mindfulness-based interventions and bereavement

CLINICAL SOCIAL WORK JOURNAL | Online – Accessed 29 October 2013 – There has been increased interest in, and evidence for, mindfulness-based interventions (MBIs) as integrative approaches for a wide variety of psychosocial issues. However, there is very little research on the use of MBIs in bereavement care and only one proposed model existing in the literature. This article presents an overview of the ... literature and uses a case study of a bereaved parent to illustrate a mindfulness-based model of bereavement care that is consistent with social work values. http://link.springer.com/article/10.1007/s10615-013-0465-y

Of related interest:

- *JOURNAL OF GERONTOLOGICAL SOCIAL WORK* | Online – 21 October 2013 – **'Older lesbians and bereavement: Experiencing the loss of a partner.'** This study is a response to the lack of knowledge about the issues for older lesbians who lose a partner. The authors examined bereavement issues for 55 older lesbians. The study asked participants to describe their concerns and experiences after losing a partner. Qualitative analysis identified several themes that ran throughout including disenfranchised grief, the loneliness of isolation, and the frustration of relentless battles. These findings indicate the need for social workers to educate themselves and others about the particular needs facing this vulnerable group of older women. http://www.tandfonline.com/doi/abs/10.1080/01634372.2013.850583

  Noted in Media Watch, 11 March 2013, #296 (p.8):

  - *JOURNAL OF LGBT ISSUES IN COUNSELING*, 2013;7(1):87-116. **'Disenfranchised grief among lesbian and gay bereaved individuals.'** Experiences of grief among lesbian and gay individuals who have encountered the death of their partner remain invisible within the larger culture and within the counseling literature. This contribution provides a conceptual review of literature regarding the bereavement process of individuals who identify as sexual minorities. http://www.tandfonline.com/doi/abs/10.1080/15538605.2013.758345

Facilitating advance care planning with ethnically diverse groups of frail, low-income elders in the U.S.: Perspectives of care managers on challenges and recommendations

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 30 October 2013 – [Study] participants identified four main sources of challenges: 1) death and dying are taboo discussion topics; 2) the dying process is beyond human control; 3) family and others hold decision-making responsibility; and, 4) planning for death and dying is a foreign concept. Participants' recommendations to address these challenges were to develop trust with elders over time; cultivate cultural knowledge and sensitivity to respect value orientations; promote designating a healthcare proxy; recognise and educate families and community leaders as critical partners in advance care planning and provide practical support as needed throughout the illness experience. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12073/abstract

Clinical and ethical challenges of palliative sedation therapy: The need for clear guidance and professional competencies

INTERNATIONAL JOURNAL OF CLINICAL PRACTICE, 2013;67(11):1086-1088. Palliative sedation therapy (PST) has become a frequent practice in end-of-life care and advocated in the literature as a less problematic alternative to practices of physician-assisted dying, such as ending patients' lives on request, or assisted suicide. However, in clinical practice, patients, healthcare professionals and other parties involved in decisions about PST are facing numerous clinical and ethical challenges. This perspective analyzes challenges associated with professional decision-making about PST and explores the recommendations of guidelines ... published in recent years. http://onlinelibrary.wiley.com/doi/10.1111/ijcp.12227/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false

Cont.

Noted in Media Watch, 15 July 2013, #314 (p.9):

- *JOURNAL OF MEDICAL ETHICS* | Online – 11 July 2013 – **'Estimating the potential life-shortening effect of continuous sedation until death: A comparison between two approaches.'** The aim of this study is to compare two approaches to estimate the potential life-shortening effect of continuous sedation until death. According to the direct approach, sedation might have had a life-shortening effect in 51% of the cases and according to the indirect approach in 84%. http://jme.bmj.com/content/early/2013/07/10/medethics-2013-101459.abstract

Noted in Media Watch, 20 May 2013, #306 (pp.10-11):

- *CURRENT OPINION IN ONCOLOGY* | Online – 9 May 2013 – **'Palliative sedation in end-of-life care.'** A number of authors have published interesting new findings on prevalence, indications, monitoring, duration and choice of drugs. A definition of palliative sedation and of its more pronounced form, deep continuous sedation, has emerged. http://journals.lww.com/co-oncology/Abstract/publishahead/Palliative_sedation_in_end_of_life_care.99618.aspx

Prison hospice

Care and companionship in an isolating environment: Inmates attending to dying peers

JOURNAL OF FORENSIC NURSING, 2013; 9(1):35-44. The purpose of this study was to examine the values, beliefs, and perceptions of end-of-life (EOL) care held by inmates caring for peers approaching the end of their lives. Face-to-face interviews were conducted with 17 male prisoners who were providing care for peers with advanced chronic illness and approaching end of life. Key themes identified: 1) getting involved 2) living the role; and, 3) transforming self through caring for others. As well, contextual features at the organizational, peer, and personal levels were identified, which either facilitated or impeded inmate caregiving. Provision of enhanced EOL care by inmate peers shows promise for improving prison community relations and morale, reducing suffering, and demonstrating care and compassion within the harsh prison environment. Implications for correctional nursing practice include providing training for inmate caregivers, including them in team meetings, and implementing grief support programs. Also, upholding nursing's code of ethics and watching for predatory behavior are critical. http://journals.lww.com/forensicnursing/Abstract/2013/03000/Care_and_Companionship_in_an_Isolating.5.aspx

Extract from *Journal of Forensic Nursing* article

This study provides clear evidence that providing compassionate care for dying peers may result in transformative experiences for inmate caregivers.

N.B. Articles and reports focused on the provision and delivery of end-of-life care for prison inmates have been highlighted in Media Watch on a fairly regular basis. A compilation of these articles and reports in a single document is available on request. Contact information at foot of p.15.

Joining together to improve outcomes: Integrating specialty palliative care into the care of patients with cancer

JOURNAL OF NATIONAL COMPREHENSIVE CANCER NETWORK, 2013;11:S-38-S-46. This article addresses the misconception that patients with cancer should undergo a definitive "transition" to palliative care at some point in their trajectory, and instead proposes that a gradual shift should occur from primary palliative care provided by the oncologist to specialty palliative care when the need exists. The goal is to help practitioners identify which patients are in need of specialty palliative care, suggest when oncologists should consider making a referral, and offer a model for sharing the responsibilities of care once palliative care clinicians become involved. http://www.jnccn.org/content/11/suppl_4/S-38.short

Cont.

Of related interest:

- *ANNALS ACADEMY OF MEDICINE SINGAPORE*, 2013;42(10):535-537. **'Psychosocial care for cancer patients – too little, too late?'** Clinical experience with patients indicates distress, anxiety and depression are prevalent from early stages of the illness. Strategies to enhance psychosocial care are presented and these include early identification through screening, training for healthcare staff working with cancer patients and support not only for patients but their caregivers as well. http://www.annals.edu.sg/pdf/42VolNo10Oct2013/V42N10p535Abstract.pdf

- *MEDPAGE* | Online – 30 October 2013 – **'Initiative raises palliative care use in cancer.'** Consultations for palliative care doubled and readmissions declined by half following a pilot study of an initiative to standardize criteria for palliative and hospice care among cancer patients. Palliative care consultations increased from 41% in a historical group of patients to 82% after the 3-month intervention. The 30-day readmission rate decreased from 36% to 17% after the intervention. Though implemented at a single institution, the criteria are applicable to any hospital, according to Kerin Adelson, MD, of Mount Sinai Medical Center in New York City. http://www.medpagetoday.com/MeetingCoverage/AdditionalMeetings/42603

- *THERAPEUTIC ADVANCES IN MEDICAL ONCOLOGY*, 2013;5(6):318-323. **'Early palliative care in cancer treatment: rationale, evidence and clinical implications.'** This review discusses the evolving evidence for early initiation of palliative care in patients with advanced cancer and ongoing barriers to care in this setting. We highlight challenges for research and care delivery and the potential for broader awareness of the demonstrated benefits of palliative care to help translate known benefits into improved outcomes for patients facing advanced cancer. http://tam.sagepub.com/content/5/6/318.abstract

Noted in Media Watch, 21 January 2013, #289 (p.9):

- *ONCOLOGY* | Online – 15 January 2013 – **'Palliative care always.'** Palliative cancer care is the integration into oncologic care of therapies that address the issues that cause physical and psychosocial suffering for the patient and family. http://www.cancernetwork.com/palliative-and-supportive-care/content/article/10165/2121558

N.B. Noted in this issue of Media Watch are several articles on integrating palliative care into comprehensive cancer care.

Australian survey of current practice and guideline use in adult cancer pain assessment and management: Perspectives of palliative care physicians

JOURNAL OF PALLIATIVE MEDICINE | Online – 29 October 2013 – Ninety-two palliative care physicians responded to a survey; 39% of the national total. The majority reported barriers to pain management, including insufficient access to non-pharmacologic interventions, poor coordination between services, and management challenges posed by co-morbidities. Forty-five percent reported using guidelines, most commonly the 'Australian Therapeutic Guidelines – Palliative Care.' Respondents were largely supportive of the development of new guidelines and implementation strategies, in particular any offering advice on specific cases of cancer pain (e.g., neuropathic), patient self-management resources, assessment of patient priorities, and disciplinary roles. Barriers to evidence-based practice identified ... might be addressed via strategies to support decision making and coordination of care (e.g., a clinical pathway). Particular attention should be paid to promoting access to non-pharmacologic interventions and patient education, and improving referral and care coordination. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0245

Of related interest:

- *JOURNAL OF PSYCHOSOCIAL ONCOLOGY* | Online – 24 October 2013 – **'Flying blind: Sources of distress for family caregivers of palliative cancer patients managing pain at home.'** This paper highlights areas of psychosocial concern for family caregivers managing a family member's cancer pain at home as they engage in pain management processes. http://www.tandfonline.com/doi/abs/10.1080/07347332.2013.856057

Research priorities in geriatric palliative care: Policy initiatives

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 October 2013 – Geriatric patients who have some combination of serious illnesses, functional limitations, frailty, and cognitive impairment represent a high cost, high need group who are not well served in the current health care system. Palliative care principles, including early advance care planning, communication about prognosis, expert symptom management, practical support for families, and presenting a variety of treatment options and their pros and cons, are intended to relieve distress and improve quality of life. Despite evidence of multiple approaches that do "work" for this population, there has been a failure to translate the successes of research and clinical demonstration projects into widespread practice. http://online.liebertpub.com/doi/pdf/10.1089/jpm.2013.9464

Of related interest:

- *PROGRESS IN PALLIATIVE CARE*, 2013;21(5):263-264. **'Recruitment into palliative care research studies: A common challenge.'** It is a well-known fact ... that once a clinical trial or study of any type opens for recruitment, the patient population of interest suddenly and mysteriously disappears. Despite evidence from careful service audits that indicate that in the previous months and years, patients fulfilling the study entry criteria, were plentiful. What could possibly account for these strange, but true, phenomena? The literature tends to attribute it to "gate-keeping" by health professionals, whereby often for the best of intentions, they seek to "protect" their patients from involvement in research. This editorial examines these practices... http://www.ingentaconnect.com/content/maney/ppc/2013/00000021/00000005/art00001

The end of AIDS: HIV infection as a chronic disease

THE LANCET | Online – 21 October 2013 – The success of antiretroviral therapy has led some people to now ask whether the end of AIDS is possible. For patients who are motivated to take therapy and who have access to lifelong treatment, AIDS-related illnesses are no longer the primary threat, but a new set of HIV-associated complications have emerged, resulting in a novel chronic disease that for many will span several decades of life. Treatment does not fully restore immune health; as a result, several inflammation-associated or immunodeficiency complications such as cardiovascular disease and cancer are increasing in importance. Cumulative toxic effects from exposure to antiretroviral drugs for decades can cause clinically-relevant metabolic disturbances and end-organ damage. Concerns are growing that the multi-morbidity associated with HIV disease could affect healthy ageing and overwhelm some health-care systems, particularly those in resource-limited regions that have yet to develop a chronic care model fully. In view of the problems inherent in the treatment and care for patients with a chronic disease that might persist for several decades, a global effort to identify a cure is now underway. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61809-7/abstract

Of related interest:

- *AMERICAN JOURNAL OF PUBLIC HEALTH*, 2013;103(10):1788-1798. **'Only your calamity: The beginnings of activism by and for people with AIDS.'** The invention of AIDS activism came soon after the AIDS epidemic emerged in gay communities in the U.S. in the early 1980s. AIDS activism by and for people with AIDS, distinct from gay activism responding to the threat of AIDS on the behalf of the whole community, started as a way of resisting the phenomenon of social death. Social death, in which people are considered "as good as dead" and denied roles in community life, posed a unique threat to people with AIDS. An organized political response to AIDS began among gay men with AIDS in San Francisco, California, and New York, New York, formalized in a foundational document later called the Denver Principles. The ideas and language of these first people with AIDS influenced later AIDS activism movements. http://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2013.301381?prevSearch=AIDS&searchHistoryKey=

Recovering an *Ars Moriendi*

THE LINACRE QUARTERLY, 2013;80(4):293-295. This special issue [of the journal] presents several articles which touch upon two increasingly important areas of clinical medicine and for which morally perilous circumstances exist, geriatrics ... and care at the end of life. The former, in light of the aging of society, is forcing us to examine our attitudes toward the elderly. End-of-life care too, in part because of an increased number of elderly, but also because ... "humanity is associated with 100% mortality," will always remain of great relevance to physicians. Physicians whose practice involves either area are served well by maintaining a clear view of the multiple dimensions and complexities sometimes attending the dying person, and of death itself. http://www.ingentaconnect.com/content/maney/lnq/2013/00000080/00000004

N.B. Contents page: http://www.ingentaconnect.com/content/maney/lnq/2013/00000080/00000004

Noted in Media Watch, 8 November 2010, #174 (p.8):

- *THE HASTINGS REPORT*, 2010;40(6):22-24. **'The art of dying well.'** The field of bioethics has, since its earliest days, debated end-of-life issues; yet American society more broadly remains ill equipped for the experience of dying. One of the pressing bioethical concerns for the coming generation is the formulation and dissemination of a framework for dying well. We need a modern version of the *Ars moriendi*, or Art of Dying, which expressed the societal and ecclesiastical response in the Middle Ages to the widespread death caused by the plague. http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=4959

Media Watch: Editorial Practice

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

Distribution

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

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch 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 next page.

American Academy of Pediatrics Policy Statement

Pediatric palliative care and hospice care commitments, guidelines and recommendations

PEDIATRICS, 2013;132(5). PPC-PHC [pediatric palliative care and pediatric hospice care] aims to relieve suffering, improve quality of life, facilitate informed decision-making, and assist in care coordination between clinicians and across sites of care. Core commitments of PPC-PHC include being patient centered and family engaged; respecting and partnering with patients and families; pursuing care that is high quality, readily accessible, and equitable; providing care across the age spectrum and life span, integrated into the continuum of care; ensuring that all clinicians can provide basic palliative care and consult PPC-PHC specialists in a timely manner; and improving care through research and quality improvement efforts. Guidelines and recommendations include ensuring that all large health care organizations serving children with life-threatening conditions have dedicated interdisciplinary PPC-PHC teams, which should develop collaborative relationships between hospital- and community-based teams; that PPC-PHC be provided as integrated multimodal care and practiced as a cornerstone of patient safety and quality for patients with life-threatening conditions; that PPC-PHC teams should facilitate clear, compassionate, and forthright discussions about medical issues and the goals of care and support families, siblings, and health care staff; that PPC-PHC be part of all pediatric education and training curricula, be an active area of research and quality improvement, and exemplify the highest ethical standards; and that PPC-PHC services be supported by financial and regulatory arrangements to ensure access to high-quality PPC-PHC by all patients with life-threatening and life-shortening diseases. http://pediatrics.aappublications.org/content/early/2013/10/23/peds.2013-2731.abstract

Of related interest:

- *AAP GRAND ROUNDS* (American Academy of Pediatrics), 2013; 30(5):58. **'What is different about children who receive palliative care?'** Subscription required to access this article. http://aapgrandrounds.aappublications.org/content/30/5/58.full
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 October 2013 – **'Specialized pediatric palliative home care: A prospective evaluation.'** The involvement of the Pediatric Palliative Home Care team led to a significant improvement of children's symptoms and QoL [quality of life] as perceived by the parents; and the parents' own QoL and burden relief significantly increased, while their psychological distress and burden significantly decreased. http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0129

The impact of "modern telecommunication" in palliative care: The views of the professionals

TELEMEDICINE & E-HEALTH | Online – 25 October 2013 – Specialized palliative care teams are typically based in larger hospitals, from where home visits, telephone consultations, and support are given directly to patients and relatives, but also to professionals working on the frontline. One of the challenges is the long distances to the patients' homes. Modern telecommunication may help overcome this, but little is known about the perceived advantages and barriers to palliative care. This study analyzed the views on modern telecommunication from specialized palliative care professionals' perspective. The authors found face-to-face communication is essential. Ethical and practical concerns were expressed on the implementation of "modern telecommunication" ... [and] ... reservations against permanent telemonitoring in the patient's home. http://online.liebertpub.com/doi/abs/10.1089/tmj.2013.0047

Extract from *Telemedicine & e-Health* article

The participants perceived a potentially added communicative value in visual telecommunication, but would never let it replace face-to-face communication.

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2013/10/media-watch/

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-care-news.php

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

PALLIMED (Hospice & Palliative Medicine Blog): http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html (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): http://centres.sg/updates/international-palliative-care-resource-center-media-watch/

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: http://palliativecarewa.asn.au/site/helpful-resources/ (Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report)

Canada

ONTARIO | Central West Palliative Care Network: http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1

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

ONTARIO | Toronto Central Hospice Palliative Care Network: http://www.tcpcn.ca/news-events

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/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online – 30 October 2013 – **'Rethinking voluntary euthanasia.'** The authors' goal is to explicate the way, and the extent to which, euthanasia can be voluntary from both the perspective of the patient and the perspective of the health care providers involved in the patient's care. They aim to challenge the way in which those engaged in ongoing philosophical debates regarding the morality of euthanasia draw distinctions between voluntary, involuntary, and non-voluntary euthanasia on the grounds that drawing the distinctions in the traditional manner fails to reflect what is important from the patient's perspective... http://jmp.oxfordjournals.org/content/early/2013/10/30/jmp.jht045.abstract

Cont.

- *JOURNAL OF HOSPITAL ADMINISTRATION* | Online – 29 October 2013 – **'Autonomy – A leading principle in the end-of-life decision making?'** According to the analysis, in no legal jurisdiction in the world the will (including consent and request) of the patient as such can serve as a full defence for decriminalisation of the life termination on request or assisted suicide. http://www.sciedu.ca/journal/index.php/jha/article/view/3151/2098

- *THE JURIST* | Online – 1 November 2013 – **'Physician-assisted suicide goes back to court in Canada.'** The case of *Carter v. Canada* is bringing the issue of physician-assisted suicide back to the Canadian courts. In 2011, Lee Carter, Hollis Johnson and the late Gloria Taylor launched a challenge to the provision in the Criminal Code of Canada that bans physician-assisted suicide. http://jurist.org/dateline/2013/11/laura-crestohl-health-law.php

- *THE LINACRE QUARTERLY*, 2013;80(4):380-386. **'Compassion and love: The antidote for sentimentalism at the end of life.'** The author identifies an increasingly common phenomenon of sentimentalist "pro-lifers" who embrace physician-assisted suicide and euthanasia because sentimental pro-life slogans readily lead to acceptance of these acts. A more principled and rational opposition to various manifestations of the culture of death including assisted suicide and euthanasia is needed. The author proposes that a robust understanding of compassion and love provide an entry point into the discussion that is both rational and emotional. http://www.ingentaconnect.com/content/maney/lnq/2013/00000080/00000004/art00010

Worth Repeating

Health care costs in the last week of life: Associations with end-of-life conversations

JAMA INTERNAL MEDICINE, 2009;169(5):480-488. Health care expenditures in the U.S. exceeded $2 trillion in 2006 and are expected to rise rapidly during the next decade. A disproportionate share is spent at the end of life (EOL). Thirty percent of Medicare expenditures are attributable to 5% of beneficiaries who die each year; about one-third of the expenditures in the last year of life is spent in the last month. Previous investigations have found that most of these costs result from life-sustaining care ... with acute care in the final 30 days of life accounting for 78% of costs incurred in the final year of life. A recent study ... showed that EOL conversations between patients and physicians are associated with fewer life-sustaining procedures and lower rates of intensive care unit (ICU) admission. These findings suggest that EOL discussions might reduce health care expenditures by reducing the use of ICU care by patients with cancer. Singer and Lowy have suggested that policies asking patients about their wishes regarding life-sustaining treatment and incorporating them into advance directives might result in cost savings by reducing undesired care at the EOL. However, other researchers have not found an association between advance directives and cost reduction. To our knowledge, the association between patient-reported discussions of EOL care preferences with their physicians and health care expenditures has not been well studied. This study sought to monetize the differences in health care use in the final week of life for patients with advanced cancer who reported having EOL discussions with their physicians compared with those who did not. The authors also examined the association between expenditures and patients' quality of life in the final week of life to determine whether costly life-sustaining care might be justified by better quality of life that these expensive procedures may afford. http://archinte.jamanetwork.com/article.aspx?articleid=414825

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