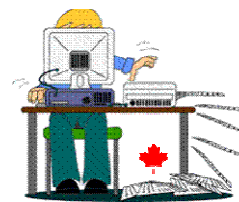


Media Watch...

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

Elder and end-of-life care in Europe: Scroll down to [Specialist Publications](#) and 'Palliative care in long-term care settings for older people' (p.8), posted online by the European Association for Palliative Care.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUÉBEC | *The Epoch Times* (Montreal) – 20 February 2013 – '**Quebec physicians launch campaign against doctor-assisted suicide.**' A group of physicians who are against doctor-assisted suicide are calling on their colleagues and the public to reject a future draft bill that would allow the possibility of "medical aid in dying" in the province. The Physicians' Alliance for Total Refusal of Euthanasia Initiative ... invited other physicians and citizens to sign a declaration against the practice. <http://www.theepochtimes.com/n2/canada/quebec-physicians-launch-campaign-against-doctor-assisted-suicide-350529.html>

Noted in Media Watch, 21 January 2013:

- QUÉBEC | *The Globe & Mail* – 16 January 2013 – '**Quebec leading the way in end-of-life issues.**' <http://www.theglobeandmail.com/life/health-and-fitness/health/andr-picard-quebec-leading-the-way-on-end-of-life-issues/article7447929/>
- ONTARIO | TV Ontario ('The Agenda') – 13 February 2013 – '**Legislating assisted suicide.**' <http://ww3.tv.org/video/188192/andre-picard-legislating-assisted-suicide>

Specialist Publications

Provincial initiative:

'Practice Support Program end-of-life module enables physicians to better support patients' (p.7), in *British Columbia Medical Journal*.

U.S.A.

Weighing risks and benefits of medical procedures

Slow medicine could have benefits

NEW HAMPSHIRE | *The Keene Sentinel* – 24 February 2013 – Slow medicine is grounded in research at the Dartmouth Medical School. Physicians are encouraged to think twice about the high risks and limited rewards of aggressive treatment for persons who are near the end of life or whose health is already compromised. Patients and families are also encouraged to consider carefully the risks and rewards of treatment. Slow medicine is not the same as the end-of-life choices that we make in our living wills. A living will states preferences for the time when one is near death and unable to communicate one's choice about life support measures. Slow medicine allows a patient to decide that he or she does not want to experience the impact of a possible procedure or course of treatment. This decision does not mean that treatment for other conditions will also be withheld. Nor is slow medicine a variety of hospice care, though there are similarities. Palliative care, to ease the symptoms of the condition, is a critical component of slow medicine. Much has been learned from the experience of the hospice movement. http://www.sentinelsource.com/opinion/columnists/staff/bauman/slow-medicine-could-have-benefits-wit-and-wisdom-by-martha/article_cf9698c1-e6bb-5815-ad8d-ff5c9361af6d.html

Just say don't: Doctors question routine tests and treatments

REUTERS | Online – 21 February 2013 – Now there are 135. That's how many medical tests, treatments and other procedures – many used for decades – physicians have now identified as almost always unnecessary and often harmful, and which doctors and patients should therefore avoid or at least seriously question. The lists of procedures, released by the professional societies of 17 medical specialties ranging from neurology and ophthalmology to thoracic surgery, are part of a campaign 'Choosing Wisely' [see sidebar right]. Organized by the American Board of Internal Medicine's foundation, it aims to get doctors to stop performing useless procedures and spread the word to patients that some don't help and might hurt. "Americans' view of healthcare is that more is better," said Dr. Glenn Stream, a family physician in Spokane, Washington, and board chairman of the American Academy of Family Physicians, which has identified 10 unnecessary procedures. "But there are a lot of things that are done frequently but don't contribute to people's health and may be harmful." In a particular case, even a procedure that provides no benefit to the vast majority of people might be appropriate. That's why the physicians emphasize that they are only advising against routine use of the usually unnecessary tests and therapies. <http://news.yahoo.com/just-dont-doctors-routine-tests-treatments-051750318.html>

Five things palliative care physicians and their patients should question

U.S. specialty societies representing more than 500,000 physicians developed lists of five things physicians and patients should question in recognition of the importance of physician and patient conversations to improve care and eliminate unnecessary tests and procedures. These lists, part of an American Board of Internal Medicine Foundation initiative, 'Choosing Wisely,' represent specific, evidence-based recommendations physicians and patients should discuss to help make wise decisions about the most appropriate care based on their individual situation.

American Academy of Hospice & Palliative Medicine: http://www.choosingwisely.org/wp-content/uploads/2013/02/AAHPM-5things-List_Web.pdf

Specialist Publications

Of related interest:

'Patient perspectives regarding communication about prognosis and end-of-life issues: How can it be optimised?' (p.10), in *Patient Education & Counseling*.

Cont.

Of related interest:

- MASSACHUSETTS | WBUR News (Boston) – 22 February 2013 – **'End-of-life conversation: From kitchen table to your doctor's office.'** 'The Conversation Project' was launched by a group of media and medical professionals who want to help families and loved ones begin to talk about end-of-life care far in advance. <http://commonhealth.wbur.org/2013/02/end-of-life-conversation-doctor>

N.B. The Conversation Project website: www.TheConversationProject.org

The reluctant caregiver

THE NEW YORK TIMES | Online – 20 February 2013 – Call her [Mrs. A.] the reluctant caregiver. She and her husband didn't invite his parents to follow them to the small city where they settled to take jobs. The elders did anyway, and as long as they stayed healthy and active, both couples maintained their own lives. Now that her mother-in-law is widowed and needy, Ms. A. feels trapped. Ashamed, too. She knows lots of adult children work much harder at caregiving yet see it as a privilege. For her, it is mere drudgery. <http://newoldage.blogs.nytimes.com/2013/02/20/the-reluctant-caregiver/?ref=health>

Bill would stop secret do-not-resuscitate orders

TEXAS | *Your Houston News* – 20 February 2013 – House Bill 1455 ... looks to stop the practice of doctors placing do-not-resuscitate (DNR) orders on a patient's chart without first getting approval from the patient or the family. Current law allows a doctor to place a DNR order on a patient's chart without first getting approval from the patient or legal guardian. Many people are unaware of this fact and have been shocked that these life and death decisions are being made without their knowledge. http://www.yourhoustonnews.com/tomball/news/legislature-bill-would-stop-secret-do-not-resuscitate-orders/article_bbb7a0dc-7b87-11e2-bb0f-0019bb2963f4.html

Bioethicist raises ethical questions over long-term life support

PUBLIC RADIO INTERNATIONAL (U.S.) | Online – 18 February 2013 – Art Caplan, a bioethicist and founding director of the Division of Medical Ethics at New York University's Langone Medical Center, says we've long assumed people in a vegetative state can no longer think, aren't aware of what's around them, and can't be conscious "Consciousness assumes that there is something there to be aware, that there's a self there or a person that's processing all this information," he said. "I think it may be the case that ... [the] ... brain is able to process certain stimuli and fire up certain circuits." What ... new technologies can reveal about brain activity is important, Caplan said, but it's important not to overstate their importance, because people end up in a comatose state for different reasons. <http://www.pri.org/stories/health/bioethicist-raises-ethical-concerns-over-life-support-12915.html>

Of related interest:

- *NEW SCIENTIST* | Online – 23 February 2013 – **'People in a vegetative state may feel pain.'** Results [of the study] question whether some diagnoses should change from unresponsive wakefulness syndrome [i.e., vegetative state] to minimally conscious, which is characterised by some level of awareness. <http://www.newscientist.com/article/mg21729055.500-people-in-a-vegetative-state-may-feel-pain.html>

[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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MONTANA | Associated Press – 20 February 2013 – **'House panel debates penalties for assisted suicide.'** A Montana House panel is considering a bill to criminalize assisted suicides and penalize the doctors and caregivers who participate in them. The Legislature has been asked to clarify the issue since a 2009 state Supreme Court ruling that nothing in state law prohibits physician-assisted suicide. http://helenair.com/news/state-and-regional/house-panel-debates-penalties-for-assisted-suicide/article_a7cde298-8f8c-5da0-8968-5e52bb612e6a.html

International

End-of-life care in Australia

Terminally ill suffer as federal palliative funds dry up

AUSTRALIA | *The Daily Telegraph* (Surry Hills, New South Wales) – 25 February 2013 – Terminally ill cancer patients and the elderly will be left without specialised end-of-life care from July when a \$500 million program at the heart of [Prime Minister] Julia Gillard's health reforms finishes. Palliative care nurses and specialists in three states have already been told they will lose their jobs and at least one five-bed service in Victoria has closed already. About 2,000 New South Wales patients will be left in the lurch when 54 palliative care workers lose their jobs in July, Palliative Care Australia estimates. <http://www.dailytelegraph.com.au/news/terminally-ill-suffer-as-federal-palliative-funds-dry-up/story-e6freuy9-1226584565780>

Are there really five stages of grief?

U.K. | BBC – 19 February 2013 – People often talk about the five stages of grief – denial, anger, bargaining, depression and acceptance. There is no set timeframe for passing through these stages, but they have become accepted as part of the normal pattern of grief. The concept originates from work in the 1960s by John Bowlby, the psychologist who became known for his work on attachment between babies and their parents, and Colin Murray-Parkes, who has written a huge amount on bereavement. They identified four stages of grief from interviews with 22 widows: numbness, searching and yearning, depression and reorganisation. Then Elisabeth Kübler-Ross, famous

for changing attitudes towards the treatment of the dying, carried out a series of interviews with terminally ill people, and devised the five stages we know of today to describe the experience of facing impending death – though didn't test them in any systematic way. <http://www.bbc.com/future/story/20130219-are-there-five-stages-of-grief>

Specialist Publications

'Sorrow and solace: Neglected areas in bereavement research' (p.7), in *Death Studies*.

Noted in Media Watch, 21 January 2013:

- *MORTALITY* | Online – 16 January 2013 – **'Elisabeth Kübler-Ross, *On death and dying*: A reappraisal.'** <http://www.tandfonline.com/doi/abs/10.1080/13576275.2012.758629>

Noted in Media Watch, 21 February 2011:

- *MACLEAN'S MAGAZINE* | Online – 14 February 2011 – **'We've been misled about how to grieve.'** <http://www2.macleans.ca/2011/02/14/weve-been-misled-about-how-to-grieve/>

Children & Young People's Health Outcomes Forum

U.K. (ENGLAND) | Together for Short Lives – 19 February 2013 – Ministers have published a full response to the recommendations made by the forum last year. The response has been compiled by the Department of Health, with a range of other agencies, government departments, health regulators, Royal Colleges [of General Practitioners, of Nursing, of Paediatrics & Child Health, and of Psychiatrists] and organisations involved in the development and delivery of child health. The Forum was an independent group set up by former Health Secretary Andrew Lansley in 2012 to help develop a new strategy for improving care for children and young people in England. The Forum made a number of recommendations for improving the health system.¹ The re-

sponse sets out a new pledge to improve child health outcomes and the next steps. http://www.dodsmonitoring.com/downloads/misc_files/CYPHOresponse.pdf

Extract from Department of Health report

The need for integrated care coordinated around and tailored to the needs of the child or young person and their family is clear and fundamental to improving their health outcomes. Integration means the joins between services and commissioning responsibilities are invisible because organisations are working in partnership to deliver the best care across whole pathways and life stages.

1. Report of the Children & Young People's Health Outcomes Forum, July 2012. <http://www.dh.gov.uk/health/files/2012/07/CYP-report.pdf>

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

What is the extent of potentially avoidable admissions amongst hospital inpatients with palliative care needs?

BMC PALLIATIVE CARE | Online – 18 February 2013 – There is clear evidence that the full range of services required to support people dying at home are far from being implemented, either in England or elsewhere. No studies to date have attempted to identify the proportion of hospital admissions that could have been avoided amongst patients with palliative care needs, given existing and current local services. This study aimed to examine the extent of potentially avoidable admissions amongst hospital patients with palliative care needs. The authors' findings challenge assumptions that, within the existing configuration of palliative and end of life health and social care services, patients with palliative care needs experience a high level of potentially avoidable hospitalisations. <http://www.biomedcentral.com/content/pdf/1472-684X-12-9.pdf>

Of related interest:

- *HEALTH EXPECTATIONS* | Online – 18 February 2013 – '**Sheffield Profile for Assessment & Referral for Care (SPARC): A survey of self-help support groups in health care.**' SPARC was developed in response to concerns that palliative care may not be reaching all people who could benefit from it. <http://onlinelibrary.wiley.com/doi/10.1111/hex.12058/abstract>
- *HEALTH SOCIOLOGY REVIEW*, 2013;21(4):373-382. '**Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities.**' The authors discuss the "Bringing Our Dying Home" project which contributes to an understanding of caring at end of life as potentially increasing social networks and community capacity. <http://hsr.e-contentmanagement.com/archives/vol/21/issue/4/article/4918/bringing-our-dying-home-how-caring-for-someone>
- *JOURNAL OF GERONTOLOGICAL NURSING*, 2013;39(1):20-28. '**To use or not to use: A literature review of factors that influence family caregivers' use of support services.**' http://www.healio.com/~media/Journals/JGN/2013/1_January/10_3928_00989134_20121107_02/10_3928_00989134_20121107_02.pdf

Developing children's palliative care in Africa through Beacon Centres: Lessons learnt

BMC PALLIATIVE CARE | Online – 18 February 2013 – The Beacon Centres programme was set up in 2009, aimed at improving access to CPC [children's palliative care] in South Africa, Uganda and Tanzania through more and better-trained health professionals and CPC clinical services of a high standard. Having identified sites in each country to develop into CPC Beacon Centres, navigators were identified who would be the 'champions' for CPC in those sites and lead a programme of training, mentorship and support. To date, 188 participants have commenced the six-month course, with 80 having completed it. CPC has been integrated into the activities of the centres and a CPC virtual resource centre set up in South Africa. The achievements from the project have been great and the work of the navigators immense, but as in all projects it has not been without its challenges. <http://www.biomedcentral.com/content/pdf/1472-684X-12-8.pdf>

Who, why and when: Stroke care unit patients seen by a palliative care service within a large metropolitan teaching hospital

BMJ SUPPORTIVE & PALLIATIVE CARE, 2013;3(1):77-83. This study indicates there are patient and condition-level factors associated with referral of stroke patients to palliative care service. It highlights factors that might better stratify hospitalised stroke patients to timely palliative care involvement, and adds an Australian perspective to limited data addressing this patient population. <http://spcare.bmj.com/content/3/1/77.abstract?sid=58faee5d-7fc0-478c-8056-3ef4292dd0fb>

Updated 25 February 2013

Media Watch Online

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/> (Scroll down to 'Palliative Care Network: Media Watch')

Australia

AUSTRALASIAN PALLIATIVE INTERNATIONAL LINK: <http://www.palliativecarewa.asn.au/news.php> (Scroll down to 'International palliative care news and journal articles')

Canada

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

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

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

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

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>

International

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>

End-of-life care in Canada

Practice Support Program end-of-life module enables physicians to better support patients

BRITISH COLUMBIA MEDICAL JOURNAL, 2013;55(2):106. In recent years, end-of-life (EOL) care has emerged as a priority area for physicians and the health care system as a whole, reflected by developments such as the 2011 provincial legislation supporting advance directives for British Columbians, and by the extent of EOL-related resources now available for patients and physicians. In September 2011, the Practice Support Program (PSP), a joint initiative of the British Columbia Medical Association and the Ministry of Health, added significantly to the resources for physicians in this area with the launch of its EOL learning module. Designed for family and specialist physicians, medical office assistants, and home and community care and palliative care nurses, the EOL learning module has proved to be one of the most popular PSP modules developed to date. In its first year, the module provided training for more than 800 participants in regions across the province. <http://www.bcmj.org/gpsc/psp-end-life-module-enables-physicians-better-support-patients>

Case study: "Do not resuscitate" stops CPR

THE CLINICAL ADVISOR (U.S.) | Online – 19 February 2013 – What happens when an elderly man tells his clinician that he wants no "heroic measures" taken to prolong his life, but his family has other ideas? In this case [study], a physician, a nurse, and the hospital that employs them all end up in court because of mixed messages. Whose instructions do you follow? As so many cases do, this one hinges on proper documentation. Without it, although the outcome might have been the same for Mr. B., it would certainly have been different for Dr. L., Ms. C., and the hospital. <http://www.clinicaladvisor.com/do-not-resuscitate-stops-cpr/article/280954/>

Current palliative and hospice care in Slovakia

CLINICAL SOCIAL WORK, 2012;5(3):5-8. Care for terminally ill and dying people in Slovakia still does not reach satisfactory standards in certain fundamental aspects. Palliative and hospice care is generally not affordable and ill people cannot afford the place where they would like to end their lives. We still do not get necessary and true information about the diagnosis and the prognosis, palliative home care is not supported, and professional support for those who would like to assist a dying person at home is missing. The authors focus attention in this contribution on the current situation in Slovakia and on the complex of palliative and hospice care as an aspect of the health and social system. http://www.clinicalsocialwork.eu/userfiles/CSW_4_2012_v5_3.pdf#page=7

Sorrow and solace: Neglected areas in bereavement research

DEATH STUDIES | Online – 20 February 2013 – The paper argues that in its focus on finding positive outcomes, bereavement research has neglected or denigrated central phenomena in intense and long-term grief: sorrow and solace. Sorrow has two elements: yearning for the dead person and grief's depression. Consolation comes into sorrow in human relationships and from inner resources. The paper notes that grief's depression can be, as William James said, the "openers of our eyes to the deepest levels of truth." The paper argues that our research would be more complete were we to include solace that comes into sorrow as one of the outcomes we can help foster. <http://www.tandfonline.com/doi/abs/10.1080/07481187.2012.673535>

Of related interest:

- *BRITISH JOURNAL OF SOCIAL WORK* | Online – 19 February 2013 – '**Developing emotional competence of social workers of end-of-life and bereavement care.**' Facing an excessive number of deaths and the intense emotions of bereaved family members, social workers who work with dying and bereaved persons are confronted with exceptional emotional challenges. <http://bjsw.oxfordjournals.org/content/early/2013/02/20/bjsw.bct030.abstract>

Cont.

- *JOURNAL OF LOSS & TRAUMA*, 2013;18(3):275-288. **'Disciplinary wounds: Has grief become the identified patient for a field gone awry?'** In the last few decades, grief and loss research in the psychological domain has focused almost exclusively on its dysfunctional nature. <http://www.tandfonline.com/doi/abs/10.1080/15325024.2012.688708>
- *MENTAL HEALTH, RELIGION & CULTURE*, 2013;16(3):291-305. **'When religion makes grief worse: Negative religious coping as associated with maladaptive emotional responding patterns.'** <http://www.tandfonline.com/doi/full/10.1080/13674676.2012.659242>

Elder and end-of-life care in Europe

Palliative care in long-term care settings for older people

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (EAPC) | Online – Accessed 18 February 2013 – With an ageing population across Europe, older people's needs for care and support are increasing in amount and complexity. Increasing numbers of older people are living with dementia. For some older people changes in physical, psychological and/or social circumstances will require a move into a long-term care facility as they can no longer be supported to live in their own homes. These older people will go on to require palliative and end of life care within these facilities, supported by staff working within, and external to, the organisation. The development of palliative care within the setting has received increased attention and many initiatives and interventions are being developed and implemented to promote high quality palliative care provision by staff working in the settings, and joint working with external staff, volunteers and relatives. There is much to learn by identifying and sharing examples of such initiatives across different countries. http://www.lancs.ac.uk/shm/research/ioelc/projects/eapc-taskforce-ltc/FinalReportLong-TermCareSettings_Jan22_2013.pdf

1. EAPC Task Force on Palliative Care in Long-Term Care Settings for Older People website: <http://www.eapcnet.eu/Themes/Organisation/Longtermcaresettings.aspx>

Noted in Media Watch, 17 December 2012:

- *THE GERONTOLOGIST* | Online – 7 December 2012 – **'Palliative care for long-term care...'** <http://gerontologist.oxfordjournals.org/content/early/2012/12/04/geront.gns154.abstract?sid=8780ce31-3bbb-43ea-906a-acb04a7dced1>

Noted in Media Watch, 19 November 2012:

- *LONG-TERM CARE MANAGEMENT* | Online – 14 November 2012 – **'Palliative care: A long-term care perspective.'** <http://long-term-care.advanceweb.com/Features/Articles/Palliative-Care-A-Long-Term-Care-Perspective.aspx>

Awareness of general practitioners concerning cancer patients' preferences for place of death: Evidence from four European countries

EUROPEAN JOURNAL OF CANCER | Online – 18 February 2013 – General Practitioners (GPs) are at the first level of contact in many European healthcare systems and they supposedly have a role in supporting cancer patients in achieving their desired place of death. A four-country (Belgium, the Netherlands, Italy and Spain) study was carried out exploring current practices. Despite the importance of being able to die in a preferred location, GPs [i.e., study participants] were often unaware about patient preferences, especially in Italy and Spain. If GPs were informed, the preference was often met in all countries, indicating room for improvement in end-of-life care. [http://www.ejancer.info/article/S0959-8049\(13\)00044-0/abstract](http://www.ejancer.info/article/S0959-8049(13)00044-0/abstract)

Cont.

Of related interest:

- *CLEVELAND CLINIC JOURNAL OF MEDICINE*, 2013;80(Suppl):S30-e-S35. **'Innovative models of home-based palliative care.'** Two home health-based programs have reported improved patient satisfaction, better utilization of services, and significant cost savings with palliative care. http://www.ccjm.org/content/80/e-Suppl_1/e-S30.abstract?sid=c20c3290-4d73-458f-8f24-786fbec24823
- *JAMA INTERNAL MEDICINE* | Online – 18 February 2013 – **'Association of hospice patients' income and care level with place of death.'** Patients with limited resources may be less likely to die at home if they are not able to access needed support beyond what is available with routine hospice care. <http://archinte.jamanetwork.com/article.aspx?articleid=1653994>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 19 February 2013 – **'The preferred place of last days: Results of a representative population-based public survey.'** This survey [in the Canadian province of Alberta] revealed 70.8% preferred to be at home near death; while 14.7% preferred a hospice/palliative care facility, 7.0% a hospital, and 1.7% a nursing home; 5.7% had no stated preference. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0262>

Peer education for advance care planning: Volunteers' perspectives on training and community engagement activities

HEALTH EXPECTATIONS, 2013;16(1):43-55. This study contributes to conceptual understandings of how volunteers may be prepared to work as peer educators by drawing on an evaluation of a training programme for peer education for advance care planning. Volunteers' personal aims ranged from working within their communities to using what they had learnt within their own families. The personal impact of peer education was considerable. Two-thirds of volunteers reported community peer education activities 1 year after the training. Those who identified strongly with a community group had the most success. <http://onlinelibrary.wiley.com/doi/10.1111/j.1369-7625.2011.00688.x/abstract>

Of related interest:

- *JOURNAL OF SOCIAL SERVICE RESEARCH* | Online – 13 February 2013 – **'Job satisfaction among volunteers with personal cancer experience.'** Findings ... indicated that the level of job satisfaction was high and stress was not ... a major concern. <http://www.tandfonline.com/doi/abs/10.1080/01488376.2013.763890>

Palliative sedation: A focus group study on the experiences of relatives

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 February 2013 – Most relatives [i.e., study participants] evaluated the provision of palliative sedation of their dying family member positively. Positive experiences were related to: the beneficial impact of palliative sedation on the patient's suffering, the opportunity that was offered to prepare for the patient's death, their involvement in the decision-making and care for the patient, and the pleasant care environment. However, the majority of the relatives were unsatisfied with one or more aspects of how information was being provided for. Some relatives were frustrated about the fact that nurses were not authorized to make decisions about the care for the patient and about the absence of physicians during week-ends. None of the relatives mentioned the loss of the ability to communicate with the patient during the sedation and the possibility of "hastening death" as disadvantages of palliative sedation. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0410>

Noted in Media Watch, 21 January 2013:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 January 2013 – **'Palliative sedation: From the family perspective.'** Study participants noticed a significant improvement in the refractory symptom with a mean reduction in the estimated suffering... <http://ajh.sagepub.com/content/early/2013/01/13/1049909112472930.abstract>

Factors affecting the LGBT population when choosing a surrogate decision maker

JOURNAL OF SOCIAL SERVICE RESEARCH, 2013;39(2):233-252. For individuals in the marginalized population of lesbian, gay, bisexual, and trans- gender persons (LGBT), choosing a health care surrogate to make medical decisions is an emotionally challenging task. These decisions become more difficult when compounded by issues of discrimination, lack of legal and social support, varying levels of relationship commitment, and complications of disclosure to family and medical professionals. Limited research exists regarding the social, legal, medical, and familial environments that impact the choice of a surrogate decision maker for an LGBT individual. This systematic review examines 14 articles to identify factors influencing individual surrogate choice and existing gaps in the literature. To remedy current research limitations, future research recommendations address the areas of design, sampling, data collection, and data analysis within diverse subgroups of the LGBT population. This review further identifies related areas of service required by members of the LGBT population relative to diversity, demographics, and social, legal, medical, and familial environments influencing their choice of a surrogate decision maker. <http://www.tandfonline.com/doi/abs/10.1080/01488376.2012.754205>

Noted in Media Watch, 25 June 2012:

- U.K. | National Health Service – 21 June 2012 – **'End-of-life care for lesbian, gay, bisexual and transgender people.'** LGBT people are at risk of not receiving high quality end of life care services, with many facing problems in terms of being treated with dignity and respect. A new guide seeks to address this. <http://www.endoflifecareforadults.nhs.uk/publications/rt-lgbt>

N.B. See Media Watch, 21 May 2012 (p.9) for a listing of articles, reports, etc., on the provision and delivery of end-of-life care for LGBT people.

Patient perspectives regarding communication about prognosis and end-of-life issues: How can it be optimised?

PATIENT EDUCATION & COUNSELING, 2013;90(3):307-314. Global themes identified included readiness for and outcomes of discussions of prognosis and end-of-life issues. Contributing to readiness were sub-themes including patients' adjustment to and acceptance of their condition (together with seven factors promoting this), doctor and patient communication skills, mutual understandings and therapeutic relationship elements. Outcomes included sub-themes of achievement of control and ability to move on. A model of the relationships between these factors, emergent cross cultural differences, and how factors may help to optimise these discussions are presented. Identified optimising factors illustrate Australian and U.S. patients' perspectives regarding how prognosis and end-of-life issues can be discussed with minimised negative impact. [http://www.pec-journal.com/article/S0738-3991\(11\)00458-7/abstract](http://www.pec-journal.com/article/S0738-3991(11)00458-7/abstract)

To be involved or not to be involved: A survey of public preferences for self-involvement in decision-making involving mental capacity (competency) within Europe

PALLIATIVE MEDICINE | Online – 20 February 2013 – The Council of Europe has recommended member states of European Union encourage their citizens to make decisions about their healthcare before they lose capacity to do so. Self-involvement in decision-making is important to [participants in this population-based survey of adults in England, Belgium, Germany, Italy, The Netherlands, Portugal and Spain]. However, a large proportion of the public prefer to not make decisions about their care in advance of incapacity. Financial hardship, educational attainment, age, and preferences regarding quality and quantity of life require further examination; these factors should be considered in relation to policy. <http://pmj.sagepub.com/content/early/2013/02/13/0269216312471883.full.pdf+html>

N.B. This issue of the journal includes several articles on communication and informed decision making and related issues. Contents page: <http://www.pec-journal.com/current>

Cont.

Noted in Media Watch, 17 December 2012:

- *JOURNAL OF AGING & HEALTH* | Online – 20 February 2013 – '**Association between anticipatory grief and problem solving among family caregivers of persons with cognitive impairment.**' Higher anticipatory grief among family caregivers impaired problem solving, which could have negative consequences for their medical decision making responsibilities. <http://jah.sagepub.com/content/early/2013/02/20/0898264313477133.abstract>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 December 2012 – '**Misunderstandings about prognosis: An approach for palliative care consultants when the patient does not seem to understand...**' <http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0142>
- *NEUROLOGY*, 2013;80(8):764-772. '**Estimating and communicating prognosis in advanced neurologic disease.**' <http://www.neurology.org/content/80/8/764.abstract>

Disparities in end-of-life care: A perspective and review of quality

POPULATION HEALTH MANAGEMENT | Online – 13 February 2013 – As the proportion of the elderly population expands and medical technology advances, a rapidly increasing percentage of health care resources is being allocated to care at the end of life (EOL). However, it is unclear whether such resources provide value. In this context, there is a need to understand how such resources are utilized and how utilization decisions are made. Variation in the use of EOL resources and decisions is attributed to patient variables, hospital factors, and the socio-cultural platform in which both patient and provider exist. This article focuses on patient variables and employs a systematic approach to advance our understanding of factors that influence EOL care. <http://online.liebertpub.com/doi/abs/10.1089/pop.2012.0061?journalCode=pop>

Of related interest:

- *ILLNESS, CRISIS & LOSS*, 2013;21(1):49-69. '**Attitudes towards bearing the cost of care in later life across the world.**' The aging population is recognized by many as a unique global phenomenon and has become a subject of interest among multidisciplinary professionals. <http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,5,10;journal,1,73;linkingpublicationresults,1:103734,1>
- *INTERNATIONAL JOURNAL OF HEALTH PLANNING & MANAGEMENT* | Online – 18 February 2013 – '**Health care expenditures from living longer – how much do they matter.**' Analysis shows that life extension costs cancel out savings from reducing morbidity. Users of economic evaluations may use this finding to estimate the bias when life extensions costs are not included in the analysis. <http://onlinelibrary.wiley.com/doi/10.1002/hpm.2164/abstract>

How do surgeons experience and cope with the death and dying of their patients? A qualitative study in the context of life-limiting illnesses

WORLD JOURNAL OF SURGERY | Online – 16 February 2013 – The essence of surgical practice ... influenced their experiences and coping mechanisms when dealing with death and dying. The following sub-themes were identified: distancing from patients; wanting to fix problems; doing in terms of operating on a patient; prominence of the surgeon's personal ability; and, high personal responsibility for patient outcomes. Giving hope and having a mixed surgical practice were some of the coping mechanisms described by participants. Death and dying are a part of surgical practice, and surgeons face challenges as they care for dying patients. Although participants stated that they felt less affected by dealing with patients dying of life-limiting illnesses than by unexpected deaths, their descriptions of their encounters, reactions, and behaviors, as well as their use of language, suggest that these deaths have a lasting impact. Potential areas for improvement of surgical practice and approaches to teaching about death and dying in surgery are addressed. <http://link.springer.com/article/10.1007/s00268-013-1948-2>

Cont.

Noted in Media Watch, 4 June 2012:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 31 May 2012 – '**On the emotional connection of medical specialists dealing with death and dying: A qualitative study of oncologists, surgeons, intensive care specialists and palliative medicine specialists.**' <http://spcare.bmj.com/content/early/2012/05/31/bmjspcare-2012-000208.abstract>

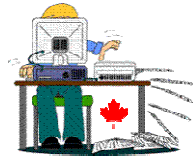
Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *INTERNATIONAL MEDICAL JOURNAL* (Malaysia), 2012;11(1):63-68 '**Euthanasia and physician-assisted suicide: A review from Islamic point of view.**' Due to globalizing trend of homogenisation of culture, changes in the health care delivery system and market economics infringing on the practice of medicine, there has been a gradual shift in the attitude of the medical community as well as the lay public towards greater acceptance of euthanasia as an option for terminally ill and dying patients. The authors review this topic from an Islamic perspective due to its significance in medical ethics and clinical practice. <http://iiumedic.net/imjm/v1/download/Volume%2011%20No%201/IMJM%20Vol11No1-2012-p63-68.pdf>

Barry R. Ashpole

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



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.

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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.

Worth Repeating

Overcoming the challenges of bedside teaching in the palliative care setting

BMJ SUPPORTIVE & PALLIATIVE CARE, 2011;1(2):193-197. Bedside teaching is the process of active learning in the presence of a patient and is one of the most traditional teaching techniques used in undergraduate medicine. Students and patients both appear to benefit from the experience of bedside experience. However, bedside teaching with medical students and palliative care patients presents a number of challenges for the patient, the learner and the educator. Key considerations ... in the palliative care context include: sensitivity to "protection," of palliative care patients by colleagues in relation to their involvement in bedside teaching; consideration of the patient's carer/relative as they will often be present for prolonged periods at the bedside; a maximum of one or two students (not the "up to six" traditionally used in this type of teaching); multiple short encounters with several patients as opposed to a longer encounter with one patient; and sensitivity to the potential impact of the session on the learner as undergraduate medical students and junior doctors may find that while worthwhile and rewarding, the teaching session is also personally emotionally challenging. <http://spcare.bmj.com/content/1/2/193.abstract?sid=68a10cdd-e64a-4b9a-b17e-947fe2be9bab>

Barry R. Ashpole
Beamsville, Ontario CANADA

'phone: 905.563.0044
e-mail: barryashpole@bellnet.ca