Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in hospice, palliative care and end-of-life issues — to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

Disadvantaged dying: Scroll down to <u>Specialist Publications</u> and 'How can we improve palliative care provision for older people? Global perspectives' (p.6), published in *BMJ Supportive & Palliative Care*.

U.S.A.

Putting the patient's quality of life first in cancer care

FLORIDA | Courier (Tampa) – 25 August 2011 – Being diagnosed with cancer can be devastating, and the treatment can take its toll in physical, emotional, social, and even spiritual ways. Palliative care providers can lessen the suffering cancer brings to patients and their families – both during treatment and at the end of life. Many people don't realize that palliative care to treat symptoms and improve a patient's quality of life can and should be given throughout their illness, not just at the end of life. http://www.flcourier.com/lifestyle/health/6049-putting-the-patients-quality-of-life-first-in-cancer-care

Hospice educator shares robotic device with dementia patients...

ILLINOIS | Courier News (Aurora) – 23 August 2011 – A kitten's soft purr or a puppy's wagging tail may be fond memories for those who appreciate the joys of animal companionship. And to individuals with Alzheimer's disease or other types of dementia, even robotic animal gestures can have positive effects on communication and well-being, according to Corey Pague of Passages Hospice. http://couriernews.suntimes.com/lifestyles/7213737-423/hospice-educator-shares-robotic-device-with-dementia-patients-in-st-charles.html

Rethinking the five stages of grief

CONNECTICUT | Hartford Courant – 22 August 2011 – More than 40 years after psychiatrist Elisabeth Kübler-Ross developed her theory on the five stages of grief, bereavement experts are questioning how well her theories have held up. "It just doesn't work anymore," said [University of Connecticut professor of psychology] Joseph Nowinski, of the Kübler-Ross model. "Technology has transformed death." As advances in medicine allow people diagnosed with terminal illnesses to live longer, the grieving process is also extended. http://articles.courant.com/2011-08-21/health/hc-uconn-grieving-0817-20110821 1 new-grief-elisabeth-k-bler-ross-depression-and-acceptance

Cont.

From Media Watch 22 January 2010:

■ THE NEW YORKER | Online article – 1 February 2010 – 'Good grief.' Though [Elisabeth] Kübler-Ross captured the range of emotions that mourners experience, new research suggests that grief and mourning don't follow a checklist; they're complicated and untidy processes, less like a progression of stages and more like an ongoing process – sometimes one that never fully ends. http://www.newyorker.com/arts/critics/atlarge/2010/02/01/100201crat_atlarge_orourke

International

70 Western Australia doctors breach code

AUSTRALIA (WESTERN AUSTRALIA) | *The Sunday Times* – 27 August 2011 – At least 70 doctors are practising medicine ... despite breaches of professional conduct or concerns that their treatment could be substandard. For example, a Kalgoorlie doctor who landed in hot water for using "inappropriate language" in front of patients now has to attend a course on communication skills. Another ... doctor found wanting in palliative care has been made to attend a forum on "end-of-life" issues. http://www.perthnow.com.au/news/western-australia/wa-doctors-breach-code/story-e6frg153-1226123439493

Do not resuscitate: Final word is with medical staff, whatever patient feels

U.K. | The Guardian - 26 August 2011 - The case of Janet Tracey who died in Addenbrooke's hospital after family claims that a "do not resuscitate" order was put in her medical notes will, no doubt, encourage health managers to check how well staff and patients are acquainted with the use of such orders. They have been given official notice to do so before. In 2000, the Department of Health in England reminded local [health] trusts they must have appropriate policies. This followed warnings from doctors that junior staff lacked proper guidance and training, and from the charity Age Concern that older people were being written off. These warnings came after Jill Baker, 67,

from Southampton, who had stomach cancer and was being treated for septicaemia, discovered after leaving hospital that a "do not resuscitate" order had been written in her notes by a junior doctor. Neither she nor her husband had been consulted. http://www.guardian.co.uk/society/2011/aug/26/do-not-resuscitate-medical-patient

General Medical Council says there is no obligation to prolong life if doctors think treatment not in patient's best interests.

Kerala healthcare model may be copied nationwide

INDIA | Business Standard (New Delhi) – 25 August 2011 – A discussion note, prepared by the India office of the World Health Organisation [WHO] and the health ministry, has identified Kerala as the country's only state that has a palliative care policy in line with WHO's public health approach in this area. The note points out that the slender southern state, with three per cent of the country's population, houses two-thirds of a total of nearly 500 palliative care centres in India. http://www.business-standard.com/india/news/kerala-healthcare-model-may-be-copied-nationwide/446965/

From Media Watch dated 9 May 2011:

■ INDIA | *The Hindu* (Chennai) – 7 May 2011 – **'Kerala shows the way.'** The Arogya Keralam Palliative Care project is being touted as India's first, and the only government initiative of its kind in entire Asia. http://www.thehindu.com/arts/magazine/article1999145.ece

Cont.

From Media Watch dated 10 January 2011:

INDIA | BBC 4 (U.K.) – 6 January 2011 – 'A model to treat the dying that could be rolled out in other nations.' Kerala has more palliative care centres than the rest of the country put together. Is this a model to treat the dying that could be rolled out in other nations ... [and] other parts of India? http://www.bbc.co.uk/iplayer/episode/b00wr9v8/Crossing Continents Palliative Care in India/

Palliative care in Africa

Who cares?

AFRICA HEALTH | Online report – Accessed 23 August 2011 – Published by the magazine Africa Health, Who Cares? Palliative Care: A Special Report was prepared by the Africa Palliative Care Association and examines palliative care on the continent. Topics include an overview of the current situation, palliative care and HIV, the impact of non-communicable disease incidence on health resources, pain and symptom management, and hospital-based and pediatric palliative care. http://www.apca.org.ug/uploads/file/Palliative%20care%20Africa%20Health%20Article.pdf

Of related interest:

- UGANDA | allAfrica.com 26 August 2011 'Palliative care extends to grassroots.' More patients will benefit from palliative care services in a new move by the Ministry of Health as minister Christine Ondoa announced they have procured enough drugs to meet the increasing demand of patients. http://allafrica.com/stories/20110826117 4.html
- UGANDA | Life Before Death 25 August 2011 – 'Nurse in the House.' In this film, one in a series of documentaries (noted in the 8 & 15 August 2011 issues of Media Watch, on p.4 and p.8, respectively), the focus is on the policies allowing nurses to prescribe oral morphine in the homes of patients.http://www.youtube.com/lifebefo redeathmovie
- UGANDA | New Vision (Kampala) 25
 August 2011 'Only 10% Ugandans
 get palliative care.' The World Health
 Organisation has advised Uganda to
 increase access to palliative care
 services for patients with life-threatening
 infections.http://www.newvision.co.ug/D/
 8/12/763564

N.B. Uganda was rated 39th in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, July 2010.

http://graphics.eiu.com/upload/QOD main final e dition Jul12 toprint.pdf

From Media Watch dated 14 February 2011:

What Africa has to teach the U.S. about hospice and palliative care

JOURNAL OF PALLIATIVE MEDICINE, 2011; 14(2):129-131. [In Africa there] is a great sense of collaboration and partnership with all components of the existing health system, as fragile and tenuous as some of them are. This posture of bringing added value as a mutually respected partner is one of the strongest impressions I have of the African hospice movement and how hospices relate to their communities. http://www.liebertonline.com/doi/pdfplus/10.1089/jpm.2010.9732

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/world/

One in ten suicides are due to illness, but the problem could be even greater, argues Demos

U.K. | Daily Telegraph - 23 August 2011 -At least 10% of suicides that take place in England involve people with either a chronic or terminal illness. It is likely that this figure may be a significant underestimate, as [the authors of 'The Truth About Suicide,' published by the "think tank" Demos¹] also found anecdotal evidence that some coroners currently choose not to include relevant health information within their inguest records, which are frequently the main input to Primary Care Trusts' suicide audits.http://www.telegraph.co.uk/health/hea Ithnews/8716316/One-in-ten-suicides-aredue-to-illness-but-the-problem-could-beeven-greater-argues-Demos.html

Quote from the Demos report:

...lack of attention paid to people with terminal or chronic illness committing suicide is a gross dereliction of duty on the part of the government and health services. The difficulty we experienced in tracking down evidence of the relationship between physical illness and suicide suggests a wilful avoidance of what is an extremely important public health issue. The results are devastating: at least 400 people with terminal or chronic illness commit suicide every year and this cannot continue to be ignored.

 'The Truth About Suicide,' Demos, August 2011.http://www.demos.co.uk/publications/thetruthaboutsuicide

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- RADIO NETHERLANDS WORLDWIDE | Online report 24 August 2011 'Dutch priest refuses euthanasia funeral.' The small Dutch town of Liempde is at the centre of an outcry after a Catholic priest refused to say a funeral mass for a man who had opted for euthanasia. The clergyman says he was only acting on the rules agreed upon by the Dutch bishops, which state that anyone who opts for euthanasia is not entitled to a church funeral. http://www.rnw.nl/english/bulletin/dutch-priest-refuses-euthanasia-funeral
- BELGIUM | Press Europe 23 August 2011 'Rise in assisted deaths.' Since 2002, and the implementation of a law that partially depenalises the practice, there have never been more cases of euthanasia. With more than 85 declared cases per month since the start of this year, there will be more than 1,000 deaths by euthanasia in 2011, as opposed to 954 in 2010. The largest group among those who exercise the right to die are men in the 60-79 age group, and 80% of cases involve patients who have been treated for cancer. http://www.presseurop.eu/en/content/news-brief-cover/878961-rise-assisted-deaths

Original source: 'L'euthanasie en hausse en Belgique,' *Le Sour* (Brussels), 23 August 2011. http://www.lesoir.be/actualite/belgique/2011-08-23/l-euthanasie-en-hausse-en-belgique-857995.php

Barry R. Ashpole

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

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

Advance directives: Limitations to completion

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 25 August 2011 – The number of elderly persons is expected to increase to 55 million by 2020, with the minority population increasing to 12.9 million, yet fewer than 30% of Americans have advance directives in place. Cultural values, religious beliefs, and family support systems are a few of the factors that influence or hinder the completion of advance directives. Health care provider perspectives regarding advance directives vary greatly with health care settings. Many primary care providers are reluctant to initiate conversations regarding advance directives for multiple reasons. Nurse practitioners cover more than 600 million office visits per year in the U.S. and are in a key position to educate, advocate, and assist in the completion of advance directives. http://aih.sagepub.com/content/early/2011/08/17/1049909111419293.abstract

Of related interest:

■ PALLIATIVE MEDICINE | Online article – 24 August 2011 – 'Paramedics experiences and expectations concerning advance directives: A prospective, questionnaire-based, bi-centre study.' The present investigation demonstrates that a dialogue bridging emergency medical and palliative care issues is necessary. The paramedics indicated that improved guidelines on end-of-life decisions and the termination of cardiopulmonary resuscitation in palliative care patients may be essential. Participants do not feel adequately trained in end-of-life care and the content of advance directives. http://pmj.sagepub.com/content/early/2011/08/24/0269216311419885.abstract

Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: Prospective cohort study

BRITISH MEDICAL JOURNAL | Online article - 25 August 2011 - On multivariate analysis, 11 core variables (pulse rate. general health status, mental test score. performance status, presence of anorexia. presence of any site of metastatic disease. presence of liver metastases. C reactive protein, white blood count, platelet count, and urea) independently predicted both two week and two month survival. Four variables had prognostic significance only for two week survival (dyspnoea, dysphagia, bone metastases, and alanine transaminase), and eight variables had prognostic significance only for two month survival (primary breast cancer, male genital cancer, tiredness, loss of weight, lymphocyte count, neutrophil count, alkaline phosphatase, and albumin).

All models performed as well as, or better than, clinicians' estimates of survival. http://www.bmj.com/content/343/bmj.d4920. abstract

Predicting and communicating prognosis in palliative care

BRITISH MEDICAL JOURNAL | Online editorial – 25 August 2011 – Doctors are rarely trained in formulating prognoses, and nor do they like doing it, so they try to avoid it. Prognosis needs to be restored as a core clinical skill, to optimise the patient's treatment and planning. http://www.bmj.com/content/343/bmj.d5171.extract

From Media Watch dated 15 August 2011:

■ JOURNAL OF PALLIATIVE CARE, 2011;27(2):89-97. 'Prognosticating in palliative care: A survey of Canadian palliative care physicians.' There was moderate agreement between respondents' perceptions of their own accuracy and that of other physicians. They believe that prognostication is important and use clinical factors to estimate survival. They often give different estimates to different information recipients. http://www.ncbi.nlm.nih.gov/pubmed/21805943

From Media Watch dated 9 May 2011:

U.S. | New York Times – 2 May 2011 – 'Figuring the odds.' Three ... palliative care specialists ... are developing a Web site that offers individual prognoses based on 18 to 20 different geriatric prognostic indexes. http://newoldage.blogs.nytimes.com/2011/05/02/figuring-the-odds/

From Media Watch dated 31 January 2011:

U.S. | Cable News Network – 24 January 2011 – 'Terminally ill patients need frank conversation about prognosis, cancer group says.' In an effort to improve the communications between doctors and patients, the American Society of Clinical Oncologists [have] released a new policy statement and a patient guide for conversations about the time when treatment options run out. http://pagingdrgupta.blogs.cnn.com/2011/01/24/terminally-ill-patients-need-frank-conversation-about-prognosis-cancer-group-says/

How can we improve palliative care provision for older people? Global perspectives

BMJ SUPPORTIVE & PALLIATIVE CARE | Online editorial – 24 August 2011 – Over the next 40 years, it is estimated that the proportion of people aged 60 years and over will double from 11% to 22% of the total world population. A 'dramatic and steady rise' in the number of deaths is also predicted. Many older people will have protracted deaths linked to a combination of long-term conditions. Further, there is mounting evidence that older people often receive what is euphemistically termed 'suboptimal' care at the end of life. In other words, they are the 'disadvantaged dying.' As a group, they often experience high physical and psychological symptom burden at the end of life, are likely to have few opportunities to express preferences for care and are still less likely to access specialist services. Those with dementia are arguably the most vulnerable to dying in circumstances far removed from contemporary Western ideals of the 'good death.' While improving palliative care provision for older people has been recognised as an international public health priority ... there is little evidence that the sheer scale of this challenge has been taken on board, either by policy makers or by the wider practitioner and academic communities. http://spcare.bmj.com/content/early/2011/08/24/bmjspcare-2011-000088.extract

Cont. on p.7

Media Watch Online

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

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx

Ontario | HPC Consultation Services: http://www.hpcconnection.ca/newsletter/inthenews.html

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

U.S.A.

Prison Terminal: http://www.prisonterminal.com/news%20media%20watch.html

International

Global | Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/all/

International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/news.htm

Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article 25 August 2011 'Assessing challenges in end-of-life conversations with elderly patients with multiple morbidities.' [In this study] three themes emerged: 1) It is more difficult ... with patients with MCM [multiple co-morbidities] and their families, as opposed to conversations with families and patients who have a clear, terminal diagnosis; 2) In deciding when to raise the subject of EOL care, participants reported that they rely on a number of physical and/or social signs to prompt these discussions; and, 3) Participants mentioned three types of approaches to initiating EOL conversations. http://ajh.sagepub.com/content/early/2011/08/17/1049909111418778.abstract
- KING'S FUND (U.K.) | Online report 23 August 2011 'Environments for care at the end of life: The King's Fund's Enhancing the Healing Environment [EHE] Programme 2008-2010.' This publication describes projects in 19 NHS [National Health Service] trusts and one prison that took part in schemes to improve the environment of care at the end of life. It describes the broader EHE programme, which has been supported by the Department of Health in a series of publications entitled 'Improving the patient experience' and goes on to present case studies of the sites that took part in the programme. http://www.kingsfund.org.uk/publications/ehe_care_environment.html
- UNIVERSITY OF SALFORD (Manchester, U.K.) | Online report Accessed 23 August 2011 'The 'conversation': Developing confidence to provide end of life care in Salford nursing homes.' The Gold Standards Framework [GSF] is an attempt to allow human life to end naturally, as peacefully and free of distressing symptoms as possible in a location [sic] and surrounded by people well known to the dying person and their family. If this cannot be the person's own home, and many would find this difficult, increasingly in the U.K. and elsewhere this may be a nursing or residential care setting. This report draws out some key challenges which became evident during an evaluation of the GSF Education Programme¹ as it was experienced by nursing home staff and residents in two nursing homes. http://usir.salford.ac.uk/17259/1/BurdettReport_Final.pdf
 - Gold Standards Framework, Education Programme http://www.goldstandardsframework.org.uk/LearningandEducation
- "INTERNATIONAL JOURNAL OF GERIATRIC PSYCHIATRY | Online article 22 August 2011 'Care at the end of life for people with dementia living in a care home: A qualitative study of staff experience and attitudes.' The staff felt warmly towards the residents and felt they could recognise when they were near death. Care staff, nurses and doctors did not see themselves as a team and communicated poorly with relatives about approaching death. The staff used opaque euphemisms and worried about being blamed. They were often unaware of or had concerns about the validity of advance care plans. They knew of the religious rituals around death but frequently misunderstood religious tradition. http://onlinelibrary.wiley.com/doi/10.1002/gps.2772/full

Costs and end-of-life care in the NICU: Lessons for the MICU?

JOURNAL OF LAW, MEDICINE & ETHICS | Online article – Accessed 23 August 2011 – The problems of economics and ethics in the NICU [neonatal intensive care unit] and the MICU [medical intensive care unit] are very different. Both, however, benefit from careful empirical research. Often, however, research looks at selected sub-populations and this gives a misleading picture of the true efficacy and cost-effectiveness of these units. Studies of the NICU often deliberately exclude patients whose illness resolves quickly. Instead, they focus on outcomes for the sickest, smallest, and highest risk babies. Some are further restricted only to infants who require mechanical ventilation. In contrast, many studies of the efficacy of MICU care describes outcomes as a function of all MICU admissions or, because they are based on Medicare data, all MICU patients who are over the age of 65. http://onlinelibrary.wiley.com/doi/10.1111/j.1748-720X.2011.00588.x/pdf

From Media Watch dated 22 August 2011:

U.S. (ILLINOIS) | Chicago Tribune – 18 August 2011 – 'Short lives, troubling questions.' How
much should be done, and at what cost, to prolong a life? Medical advances present doctors with
that dilemma every day, whether they deal with critically ill infants or adults with end-stage cancer.
http://www.chicagotribune.com/news/opinion/editorials/ct-edit-twins-20110818,0,2528437.story

Depression in palliative care settings: The need for training for nurses and other health professionals to improve patients' pathways to care

NURSE EDUCATION TODAY | Online article – 22 August 2011 – Depression is highly prevalent in patients receiving palliative care; however, detection rates are low, with many patients who suffer with depression continuing to go undetected and untreated. A number of factors unique to this setting, as well as issues relating to staff knowledge and self-efficacy working with depression, may impede the detection of patients who are depressed by professional health care staff. Although programmes aimed to train nurses and other allied health staff in depression may be an effective way to improve detection rates, there have been few studies investigating the efficacy of these interventions. This article draws upon recent literature to provide a narrative review of barriers to detection and factors relating to professional palliative care staffs' ability to provide pathways to care for patients who suffer with depression in this setting. http://www.nurseeducationtoday.com/article/S0260-6917(11)00184-5/abstract

From Media Watch dated 20 June 2011:

BMC PALLIATIVE CARE | Online article – 13 June 2011 – 'Intervention for depression among palliative care patients and their families: A study protocol for evaluation of a training program for professional care staff.' This article presents a study protocol to evaluate a training intervention for non-physician palliative care staff to improve the recognition of depression and provide support for depressed patients and their family members. http://www.biomedcentral.com/content/pdf/1472-684x-10-11.pdf

Feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: A phase II randomized controlled trial of a brief palliative care psychotherapy

PALLIATIVE MEDICINE | Online article - 22 August 2011 - The authors' found no significant differences between groups on measures of potential effectiveness at any time. There was a reduction in dignityrelated distress across both groups. The intervention group outperformed the control group on all the acceptability items at both follow-ups. These were significant for feeling that Dignity Therapy ... had made their life more meaningful at two-week follow-up, and that it would help their families at both follow-ups. Although Dignity Therapy took longer to deliver than expected, this intervention may be a way of enhancing the end-of-life experiences of residents. http://pmj.sagepub.com/content/early/2011/0 8/20/0269216311418145.abstract

Jumping into the world of social media with *Palliative Medicine*

PALLIATIVE MEDICINE, 2011;25(6):611-612. Social Media? Lady Gaga? Demi Moore? Facebook? Tweets? Blogs? What do I care where Stephen Fry is having dinner tonight? What has this to do with palliative care and in particular this journal? In June, Palliative Medicine made the jump into the world of social media with both Facebook (Palliative Medicine) and Twitter (@PalliativeMedJ) accounts. What is this thing called social media? http://pmj.sagepub.com/content/25/6/611.extract

From Media Watch dated 11 July 2011:

CANADA (MANITOBA) | PostMedia News – 6 July 2011 – 'Therapy helps dying patients tend to unfinished business, Canadian study says.' Researchers have come up with a list of questions to help terminally ill people share their memories, hopes and regrets as they look back on their lives. http://www.canada.com/health/Therapy+helps+dying+patients+tend+unfinished+business+Canadian+study+says/5060980/story.html

Partnerships between pediatric palliative care and psychiatry

PEDIATRIC CLINICS OF NORTH AMERICA, 2011;58(4):1025-1039. Given the psychosocial and emotional needs of children and their families it is clear that psychiatrists can, and do, play a role in delivering pediatric palliative care. In this article the partnership between pediatric palliative care and psychiatry is explored. The authors present an overview of pediatric palliative care followed by a summary of some of the roles for psychiatry. Two innovative pediatric palliative care programs that psychiatrists may or may not be aware of are described. Finally, some challenges that are faced in further developing this partnership and suggestions for future research are discussed. http://www.pediatric.theclinics.com/article/S0031-3955(11)00062-9/abstract

From Media Watch dated 23 May 2011:

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

"It's my pleasure?"

The views of palliative care patients about being asked to participate in research

PROGRESS IN PALLIATIVE CARE, 2011:19(4):159-164. The involvement of hospice users in research is important and has the capacity to produce a diverse, but significant impact on those involved. Not only does their involvement demonstrate the potential to shape service provision, it also reveals the therapeutic benefits to individuals with a life-limiting illness of simply taking part. http://www.ingentaconnect.com/content/maney/ppc/2011/00000019/00000004/art00001

From Media Watch dated 15 August 2011:

- JOURNAL OF SUPPORTIVE ONCOLOGY | Online report 16 August 2011 'Experts: Palliative care can begin before the end.' Palliative care, once limited to the last days before death, is ripe for research and essential to improving patient quality of life, according to speakers at a summit sponsored by the National Institute of Nursing Research and National Institutes of Health partners. http://jso.imng.com/single-view/experts-palliative-care-can-begin-before-the-end/4155306c72.html
- PALLIATIVE MEDICINE | Online article 'Designing and conducting randomized controlled trials in palliative care: A summary of discussions from the 2010 clinical research forum of the Australian Palliative Care Clinical Studies Collaborative.' Rigorous clinical research in palliative care is challenging but achievable. The aim of this paper is to highlight practical considerations from a forum held to discuss these issues by active palliative care clinical researchers. http://pmj.sagepub.com/content/early/2011/08/13/0269216311417036.abstract

Who is the key worker in palliative home care?

SCANDINAVIAN JOURNAL OF PRIMARY HEALTH CARE | Online article – 23 August 2011 – This study aimed to explore who acts as key worker and who ought to take on this role in the views of patients, relatives, and primary care professionals. Patients, relatives, GPs, and CNs [community nurses] most often saw themselves as having been the key worker. When asked about the ideal key worker, most patients and relatives pointed to the GP. Using patients' views as reference, the authors found very limited agreement with relatives, with GPs and with CNs. Poor agreement between patients, relatives, and professionals on actual and ideal key worker emphasizes the need for matching expectations and clear communication about task distribution in palliative home care. http://informahealthcare.com/doi/abs/10.3109/02813432.2011.603282

Assisted (or facilitated) death

Representative sample of recent articles, etc:

■ AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article – 25 August 2011 – 'Hospice-assisted death? A study of Oregon hospices on Death with Dignity.' Nearly 90% of terminally ill patients who have used Oregon's distinctive death with dignity law to receive a medication to end their lives are enrolled in hospice care programs. In 2009-2010, the authors conducted a study of the policies developed by Oregon hospices to address patient inquiries and requests for death with dignity. The study examined the stated hospice values and positions and identified the boundaries to participation drawn by the hospice programs to protect personal and programmatic integrity. The boundaries were drawn around six key caregiving considerations: 1) language regarding physician-assisted death; 2) informed decision making by patients; 3) collaboration with physicians; 4) provision of lethal medication; 5) assistance in the patient's act of taking the medication; and, 6) staff presence at the time of medication ingestion. http://aih.sagepub.com/content/early/2011/08/17/1049909111418637.abstract

Media Watch: Editorial Practice

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

Distribution

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

Links to Sources

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- 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.



http://www.worldday.org/

Worth Repeating

Palliative medicine and modern technology

CANADIAN MEDICAL ASSOCIATION JOURNAL, 1999;161(9);1120-1121. Palliative care and modern technology are often viewed as being somehow antithetical. This misunderstanding arose with the development of palliative care in the late 1960s and early 1970s as a response to care that was seen as impersonal, dehumanized and overly dependent on technology. The successes of the scientific method and the biomedical model had led Western health care to an almost exclusive focus on the pathophysiology of disease rather than the experience of illness. Investigation, diagnosis, cure and the prolongation of life – initially the means to the broader end of alleviating suffering - became ends in themselves, and the human focus in medicine exemplified by the Oslerian approach was sacrificed to science and technology. Terminally ill patients, especially those with cancer, were often subjected to aggressive attempts at cure even when they were likely to be futile. All too frequently, patient care was portrayed as a war to be won or lost. On such a battlefield, patients in the process of dying could only be seen as the ultimate losers. These attitudes persist today. Although over a generation has passed since the development of modern palliative medicine, patients are still being told that "Nothing more can be done" when further therapy is unlikely to prolong life. A sense of therapeutic impotence frequently leads to therapeutic excess. The fear of excessive measures to prolong life contributes to popular support for euthanasia and assisted suicide and fuels the sense that modern technology is at odds with the care of the terminally ill. http://www.cmaj.ca/content/161/9/1120.full

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