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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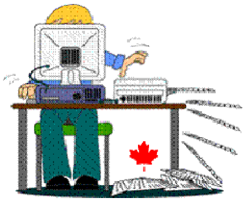


Compiled & Annotated by Barry R. Ashpole

Seven pledges to patients at the end of their lives: Scroll down to International and 'GPs and nurses launch charter for end of life care' (p.7), for a report broadcast by BBC News.

Canada

The art of grief: Living with a hole in your heart

BRITISH COLUMBIA | *Vancouver Sun* – 4 June 2011 – Many of us are ill at ease with death, grieving, mourning and sorrow. Given our nervousness about death, many respond to those who grieve with platitudes about "closure" or about how "time will heal your pain." Some come up with magical-sounding things about Jesus, or speak of cosmic New Age souls who choose the time of their death. Practical types provide unhelpful tips about how it's time to "start living your normal life now." There is evidence that fear of sorrow may be particularly strong on the West Coast, where people are more suspicious than most about religious organizations and their death rituals. http://www.vancouversun.com/grief+Living+with+hole+your+heart/4893372/story.html

Hospice to be approved despite residents' concerns

BRITISH COLUMBIA | *The Province* (Vancouver) – 2 June 2010 – The University of British Columbia [UBC] is going ahead with a controversial plan to build a hospice beside a high-priced condo tower despite protests from enraged Asian tenants who claim "ghosts of the dead will invade and harass the living." UBC spokesman Stephen Owen confirmed ... the school's board approved the hospice plan ... after making "significant and detailed" efforts to mitigate resident concerns.http://www.theprovince.com/business/hopsice+approved+despite+residents+concerns/4884345/story.html

From Media Watch dated 17 January 2011:

- BRITISH COLUMBIA | CTV News – 13 January 2011 – **'Fear of ghosts spawns protest against ... hospice.'** Asian condo owners at the University of B.C. are protesting plans to build a hospice nearby. The site was selected for the hospice after a four-year review of twelve possible locations. http://www.ctvbc.ctv.ca/servlet/an/local/CTVNews/20110113/bc_ubc_hospice_110113/20110113?hub=BritishColumbiaHome

Health-care reform needed to ensure financial sustainability of system: Business community

BRITISH COLUMBIA | *Vancouver Sun* – 2 June 2011 – Vancouver's business community jumped headlong into the health care debate with the release of an ambitious report aimed at curbing spiralling costs and improving patient services. The report[1] ... offers eight recommendations to reform B.C.'s current system — the result of a two-year study conducted by a special committee made up of health care representatives on behalf of the Vancouver Board of Trade. "The issue of health care delivery, quality and sustainability has become urgent to the point where the business community is starting to worry about it as a potential weakness in Canadian prosperity long-term, and we need to help solve some of these problems." According to the report, health care spending in B.C. is growing at a rate much faster than the increase in government revenues and will reach 50% of the total provincial budget "sooner rather than later." That's already the case in Ontario and Quebec, and "every province is essentially on that same trajectory," said the report's author.http://www.vancouversun.com/health/Health+care+reform+needed+ensure+financial+sustainability+system+business+community/4875551/story.html

Recommendation #6

That the provincial government initiate a public dialogue on end-of-life care. Such a discussion should include the recommendation that individuals should have their wishes for end-of-life care documented as early as possible and communicated to health care providers and appropriate decision-makers.

1. *The Joint Pursuit of Value: How the Business Community, Government, Patients & Providers Can Work Together to Improve BC's Health Care System*, Health, Wellness & Well-being Task Force, Vancouver Board of Trade, June 2011. http://www.boardoftrade.com/files/PDF/Policy/2011/TheJointPursuiteOfValue-Policy%20Paper-FinalMAY30-11.pdf

Of related interest:

- ONTARIO | *Digital Journal* – 3 June 2011 – **'How will we die in Ontario?'** For far too many, palliative care could be introduced far too late in the dying process. Some will never hear what palliative care they could be offered as the medical profession fights to save their lives. This fact is highlighted when you consider that 10% of those who die in hospital do not have a record of their death being in hospital. Palliative care can improve the quality of life of patients. Instead of focusing on treating late stage disease patients can focus on living without pain. So why are patients not being served at a better rate at the end of life? For one, the funding dollars are tight and for another many of those who would be best cared for in the palliative setting are being cared for at home until a medical crisis. Another hindrance is that even for professionals navigating through the system is difficult. http://www.digitaljournal.com/article/307559

Specialist Publications

Of particular interest:

'The question of public support for assisted suicide or euthanasia in Canada' (p.13), published in *BMJ Supportive & Palliative* Care

N.B. Available is **'Assisted (or Facilitated) Death: The Debate in Canada,'** which summarizes notable developments (as reported in past issues of Media Watch) – highlighting also those in other countries – that inform discussion of the issue in Canada. Contact information at foot of (p.13).

U.S.A.

Rely on hospice

NEW YORK TIMES | Online OpEd – 1 June 2011 – Medicare should stop paying for futile end-of-life care provided in intensive care units (ICUs). In other words, hospital care for the terminally ill that has no curative potential and is solely life-prolonging should not be covered. Hospital costs represent the single largest component of Medicare's total expenditures, and approximately a quarter of the $450 billion that Medicare spent last year went to pay for care in patients' last years of life. A significant portion of this spending, as much as a third, was wasted and even detracted from patients' quality of life. Granted, proposing to cease coverage of end-of-life care in ICUs is easy. Actually implementing the idea would be politically explosive, as the vitriolic health reform debates over alleged "death panels" showed in 2009. Also, distinguishing severely ill patients who are treatable from those who are terminal is not always simple. Yet high quality hospice programs with professional "care managers" who help patients and their loved ones make more informed decisions have been shown to improve patient well being and save money. http://www.nytimes.com/roomfordebate/2011/06/01/what-medicare-services-to-cut-starting-today/rely-on-hospice

Specialist Publications

Of particular interest:

'Hospice use among African Americans, Asians, Hispanics, and Whites: Implications for practice' (p.8), published in the *American Journal of Hospice & Palliative Care.*

Of related interest:

- MASSACHUSETTS | *Boston Globe* – 6 June 2011 – **'End-of-life economics.'** Amid increasing anxieties over the rising cost of health care, and the contentious debates in particular surrounding a potential Medicare overhaul, a new nationwide poll from Suffolk University's Political Research Center is believed to be the first to directly link health care spending for seniors with end-of-life choices.http://www.boston.com/lifestyle/health/articles/2011/06/06/pulling_the_plug__at_what_cost/

- PENNSYLVANIA | *Pittsburgh Tribune-Review* – 6 June 2011 – **'Aggressive care to the end: Who pays?'** As lawmakers argue about ways to cut [Medicare] costs, many experts say the government wastes billions of dollars on unnecessary care for dying patients. This is not about death panels, the fictitious health arbiters that supposedly would decide whether there's money to pay for Grandma's care. http://www.pittsburghlive.com/x/pittsburghtrib/news/pittsburgh/s_740510.html

- OREGON | *Mail Tribune* (Medford) – 2 June 2011 – **'Could Oregon's end-of-life care standard save Medicare?'** Oregon has consistently ranked in the bottom 5 to 10% in cost per Medicare beneficiary. How are we different from areas that spend so much more than we do? One area of clear difference is our approach to end of life. Although Oregon developed a reputation for allowing physician-assisted suicide, few ... have availed themselves of that service. Instead, we have developed a medical culture that encourages both physicians and patients to openly discuss end-of-life-care.http://www.mailtribune.com/apps/pbcs.dll/article?AID=/20110602/OPINION/106020306/-1/NEWSMAP

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GALLUP | Online report – 31 May 2011 – **'Doctor-assisted suicide is moral issue dividing Americans most.'** Doctor-assisted suicide emerges as the most controversial cultural issue in Gallup's 2011 Values & Beliefs poll, with Americans divided 45% vs. 48% over whether it is morally acceptable or morally wrong. http://www.gallup.com/poll/147842/Doctor-Assisted-Suicide-Moral-Issue-Dividing-Americans.aspx

International

Medicalising death

IRELAND | *Irish Times* – 3 June 2011 – When Ivan Illich with his stern take on western medicine referred to the medicalisation of death, he touched a troubling sore. Medicine had in a sense lost its soul. It had become fixated with labelling diseases, with the implication that there was a cure for all ills. Without that cure, medicine had failed and doctors had met the ultimate act of consumer resistance. No longer was death seen as a natural event, one that affects up to 30,000 people in Ireland every year. Society had lost the ability to accept dying and death as meaningful aspects of life and was entering the world of futile treatments and inappropriate resuscitations. These and other issues will be highlighted at a conference in Dublin in October [2010] organised by the Forum on End of Life which is a project of the Irish Hospice Foundation. It will provide an opportunity to take stock of whether Ireland has improved its ability to deal with dying, death and bereavement. Has progress been made, for example, in ensuring that more people have the choice of dying at home rather than in hospitals or nursing homes? A national audit on end-of-life care in hospitals showed that about 25 per cent of them could if there were proper supports.http://www.irishtimes.com/newspaper/opinion/2011/0603/1224298322392.html

Also on the conference agenda

Despite many good operators, an unregulated industry fails to inspire confidence. The forum has urged the Government to set up an office to regulate the sector, with frequent inspections of facilities and enforcement of mandatory training for funeral personnel.[1]

1. *The Funeral Industry in Ireland: The Road to Reform*, The National Council of the Forum on End of Life discussion document can now be downloaded at: http://www.endoflife.ie/news/updates.aspx?article=abbdd119-6763-44c4-b1c8-2d275c5478f3

Global: Tens of millions face death in agony

HUMAN RIGHTS WATCH | Press release – 2 June 2011 – Tens of millions of people worldwide are denied access to inexpensive medications for severe pain, Human Rights Watch said in a [new] report.[1] The report details the failure of many governments to take even basic steps to ensure that people with severe pain due to cancer, HIV, and other serious illnesses have access to palliative care, a health service that seeks to improve quality of life. As a result, millions of patients live and die in great agony that could easily be prevented, Human Rights Watch said. Experts estimate that 60% of those who die each year in low- and middle-income countries – a staggering 33 million people – need palliative care. In these countries, most cancer patients are diagnosed when they already have advanced disease and can no longer be cured. The only treatment option is palliative care. In high-income countries, palliative care needs are increasing with aging populations and the resulting higher cancer incidence.http://www.hrw.org/en/news/2011/06/02/global-tens-millions-face-death-agony

Worldwide, palliative care needs are enormous, but many governments simply ignore them. There's no excuse for letting people suffer from severe pain when inexpensive medications are available to help them. Laura Thomas, Human Rights Watch

1. *Global State of Pain Treatment: Access to Medicines & Palliative Care*, Human Rights Watch, June 2011. http://www.hrw.org/node/98936

Cont.

Of related interest:

- UGANDA | *The Monitor* (Kampala) – 1 June 2011 – **'Hospice begins making pain killers.'** Hospice Uganda is now reconstituting opium imported from Scotland ... to make oral morphine ... [which is used in palliative care for cancer and HIV/Aids patients]. "...because of our ... track record and the quality system that we have in place, we were allowed to make morphine," [said] Dr. Eddie Mwebesa, the clinical director of Hospice Uganda. http://allafrica.com/stories/201105311294.html

From Media Watch dated 16 May 2011:

- UKRAINE | Associated Press – 12 May 2011 – **'Ukrainian cancer patients denied pain relief.'** Hundreds of thousands of Ukrainians who suffer from terminal illnesses are denied proper pain relief, Human Rights Watch said in a report, urging Ukrainian authorities to adopt international guidelines for pain management.[1] http://www.seattlepi.com/news/article/Ukrainian-cancer-patients-denied-pain-relief-1376503.php

  1. *Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care*, Human Rights Watch, 12 May 2011. http://www.hrw.org/en/reports/2011/05/12/uncontrolled-pain-0

Lien Foundation's study on how to improve Singapore's quality of death draws 30 leading voices

SINGAPORE | Lien Foundation press release – 2 June 2011 – 'Living with the End in Mind' is the first-ever study of its kind, the result of the Lien Foundation's consultations with 30 movers and shakers from the medical, community and academic fields. Their vigorous responses reflected a shared sense of urgency for the need to improve end-of-life care in Singapore, as part of the overall quality of life. This study is a follow-through from the results of the global Quality of Death Index conducted last year by the Economist Intelligence Unit that placed Singapore 18th among the 40 countries surveyed. This study is part inquiry, part policy analysis and part idea generation. http://lienfoundation.org/pdf/news/2011/LWEIM%20Press%20Release%20Final.pdf

From Media Watch dated 19 July 2011:

- ECONOMIST INTELLIGENCE UNIT (EIU) | Online posting – 14 July 2010 – **'The U.K. has the highest quality of death.'** According to the Worldwide Palliative Care Alliance, while more than 100 million patients and family care-givers worldwide need palliative care annually, less than 8% of this number actually receives it. With this in mind, the EIU has devised a 'quality of death' index [commissioned by the Singapore-based Lien Foundation] to rank countries according to their provision of end-of-life care. http://www.eiuresources.com/mediadir/default.asp?PR=2010071401

  N.B. Singapore was rated 18th in *The Quality of Death: Ranking End of-life-Care Across the World*, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

Expressions of grief

Psychologists issue caution as grieving mothers turn to reborn baby dolls

AUSTRALIA (VICTORIA) | *Herald Sun* (Melbourne) – 31 May 2011 – Dolls that look uncannily like real babies provide comfort for elderly dementia patients but divide opinion among psychologists as the dolls are bought by grieving mothers. The 5kg lifelike "reborn babies" come with hair, veins, nails, eyelashes, and even a spot of saliva around the mouth, and are sought after by doll collectors. But some reborns are being purchased by women mourning dead children – sparking mixed reactions from psychologists. Sandra Wheatley... says a "reborn baby" could be helpful as a "physical tool to help them mourn the one that they have lost. It allows them to adjust slowly at their own pace to a situation that they do not want to be in," she said. "The use of the doll as a transitional tool could be a very healthy thing, as long as it does not go on too long." However, Dr. Ingrid Collins... said the dolls risked creating more problems. "When you have mourned your child, what do you do with the doll?" she said. "Do you bury it again?" http://www.heraldsun.com.au/lifestyle/the-other-side/reborn-babies-are-a-little-too-real/story-e6frfhk6-1226065583127

Sheikha Moza launches [Qatar] national cancer strategy

QATAR | *Gulf Times* – 31 May 2011 – [Her Highness] Sheikha Moza bint Nasser [has] launched a National Cancer Strategy: The Pathway to Excellence [2011-2016] which aims to put the state's cancer services at the forefront globally by 2016. Cancer accounts for 10% of all deaths in the country but it is low compared to many other places in the world. In the U.K., 27% of deaths are caused by cancer. An ageing and growing population in Qatar, which is expected to increase to 20% from present 2% by 2050, means cancer cases could double by 2030, however. The successful implementation of the new strategy will mean that instead of Qataris going abroad for cancer care, people from the Gulf region and further afield will want to come to Doha for cancer treatment. http://www.gulf-times.com/site/topics/article.asp?cu_no=2&item_no=438061&version=1&template_id=57&parent_id=56

Qatar National Cancer Strategy recommendation

More investment in palliative care, including a specialist palliative care facility and provision at home; support for survivors completing treatment.

Institute for Oncology & Radiology of Serbia a centre for palliative care...

SERBIA | *Balkan Business News* – 31 May 2011 – [Minister of Health Zoran Stankovic] ... presented the 'Development of Palliative Care in Serbia' project. Stankovic said that 476 people were trained last year through palliative care services and added that €3.5 million are earmarked ... for this project. €2.7 million are intended for education in palliative care and the establishment of specialised agencies, and €0.8 million for the purchase of vehicles for the teams for palliative care and the purchase of equipment for these units in hospitals. http://www.balkans.com/open-news.php?uniquenumber=106938

Media Watch: Editorial Practice

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

Distribution

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

Links to Sources

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

Something Missed or Overlooked?

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

GPs and nurses launch charter for end of life care

U.K. | BBC News – 31 May 2011 – Health staff have made seven pledges to patients at the end of their lives [see sidebar]. The Charter for End of Life Care aims to ensure patients' remaining days are as comfortable as possible. It includes calls for healthcare teams to do all they can to preserve patients' independence, dignity and sense of personal control. The document, created by the Royal College of General Practitioners and the Royal College of Nursing, will be sent to 8,500 GP practices in England. The charter is the result of collaboration between patients, nurses, GPs and others involved in health and social care. Primary care professionals are encouraged to help patients think ahead to identify choices they may face and assist them to record their decisions clearly. Healthcare teams will also pledge to support friends and relatives, both as patients near the end of their lives and through the subsequent bereavement process. The Royal College of Nursing said that although end of life services have improved in recent years, there was still a long way to go before they were confident patients will receive the best possible care. http://www.bbc.co.uk/news/health-13601446

Charter for End of Life Care pledges:

- Listen to your wishes about the remainder of your life, including your final days and hours, answer as best we can any questions that you have and provide you with the information that you feel you need.
- Help you think ahead so as to identify the choices that you may face, assist you to record your decisions and do our best to ensure that your wishes are fulfilled, wherever possible, by all those who offer you care and support.
- Talk with you and the people who are important to you about your future needs. We will do this as often as you feel the need, so that you can all understand and prepare for everything that is likely to happen.
- Endeavour to ensure clear written communication of your needs and wishes to those who offer you care and support both within and outside of our surgery hours.
- Do our utmost to ensure that your remaining days and nights are as comfortable as possible, and that you receive all the particular specialist care and emotional and spiritual support that you need.
- Do all we can to help you preserve your independence, dignity and sense of personal control throughout the course of your illness.
- Support the people who are important to you, both as you approach the end of your life and during their bereavement.

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/world/world/

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

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

Hospice use among African Americans, Asians, Hispanics, and Whites: Implications for practice

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE | Online article – 1 June 2011 – This study examined the characteristics of individuals in hospice care by racial/ethnic groups. More females than males [i.e., study participants] were represented. Spouse caregivers were most common for Whites (35%) and Asian/Pacific Islanders (36%). However, "other" (41%) caregivers were most frequent for African Americans and daughters (33%) were most often caregivers for Hispanics. Racial/ethnic minorities were more likely to rely on Medicaid than Whites (10-70% vs. 4%) and African Americans were most likely to be transferred from hospital (57%), whereas Whites were referred from assisted living/nursing homes more frequently than others(16% vs. 7-10%). As the hospice settings become more racially/ethnically diverse, it is essential to attend to the different circumstances and needs of the various groups in providing optimal care. http://ajh.sagepub.com/content/early/2011/05/31/1049909111410559.abstract

Of related interest:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE* | Online article – 1 June 2011 – **'Cultural competency and diversity among hospice palliative care volunteers.'** Because of changing demographic trends and ethnic minorities underutilizing hospice palliative care services, this research examined the current state of culturally competent care in a hospice setting. The findings reveal that volunteers [i.e., study participants] encountered cultural clashes when their level of cultural competency was weak. They revealed there was a lack of adequate cultural competency training with their hospice, and ... there was a lack of ethnic, cultural and linguistic diversity among hospice volunteers. http://ajh.sagepub.com/content/early/2011/05/31/1049909111410415.abstract

Balancing punishment and compassion for seriously ill prisoners

ANNALS OF INTERNAL MEDICINE | Online OpEd – 31 May 2011 – Compassionate release is a program that allows some eligible, seriously ill prisoners to die outside of prison before sentence completion. It became a matter of federal statute in 1984 and has been adopted by most U.S. prison jurisdictions. Incarceration is justified on 4 principles: retribution, rehabilitation, deterrence, and incapacitation. Compassionate release derives from the theory that changes in health status may affect these principles and thus alter justification for incarceration and sentence completion. The medical profession is intricately involved in this process because eligibility for consideration for compassionate release is generally based on medical evidence. Many policy experts are calling for broader use of compassionate release due to many factors, such as an aging prison population, overcrowding, the increasing deaths in custody, and the soaring medical costs of the criminal justice system. Even so, the medical eligibility criteria of many compassionate-release guidelines – which often assume a definitive prognosis – are clinically flawed and procedural barriers may further limit their rational application. We propose changes to address these flaws. http://www.annals.org/content/early/2011/05/31/0003-4819-155-2-201107190-00348?aimhp

Of related interest:

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2011;364(22):2081-2083. **'Medicine and the epidemic of incarceration in the U.S.'** Over the past 40 years, the number of people in U.S. prisons has increased by more than 600% – an unprecedented expansion of the criminal justice system. On 1 January 2008, one of every 100 adults, or more than 2.3 million people, were behind bars. An estimated 10 million Americans are incarcerated each year. With only 5% of the world's population, the U.S. has a quarter of the world's prisoners. No other country locks up more of its citizens. http://www.nejm.org/doi/full/10.1056/NEJMp1102385

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.13).

How to discuss death with children and families?

BULLETIN DU CANCER, 2001 | Online French language article – 3 June 2011 – Taking care of a child or an adolescent in palliative stage is a testing work for health professionals in paediatric onco-hematology. The communication with the child at the end of life and his family is delicate but however essential to ensure quality cares while supporting trust. The continuation of a genuine relation and a regular information concerning the child's health help the parents to progressively understand the lack of possible cure and the future death of their child. This anticipation also allows to possibly discuss about conditions and place of death of the ill child or adolescent. The child or adolescent himself at the end of life can also feel the need for speaking about his situation. It is then for the adult, parent or health professional, to share with him his questionings and his possible worries in order to reduce his loneliness and his fears. To let be guided by the child allows to respect his progression and his wish to know more about it or not. Finally a support must also be offered for the siblings. http://www.john-libbey-eurotext.fr/en/revues/medecine/bdc/e-docs/00/04/67/43/resume.phtml

Of related interest:

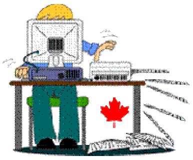
- *JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY*, 2011;1(1):11-12. **'Palliative care for adolescents and young adults: A pediatric perspective.'** Adolescent and young adult (AYA) oncology patients are a diverse group with care delivered by both pediatric and adult providers. This diversity in treatment settings has been a challenge to improving survival rates for AYAs through clinical trials and may also account for the paucity of literature on palliative care in this population. AYAs are unique, caught between childhood and adulthood both medically and developmentally. http://www.liebertonline.com/doi/abs/10.1089/jayao.2011.1503

From Media Watch dated 6 September 2010:

- *JOURNAL OF PEDIATRIC HEALTH CARE*, 2010;24(5):286-291. **'Including the perspective of the adolescent in palliative care preferences.'** A pediatric hospital in the [U.S.] Midwest uses a communication tool (CCCT) to facilitate conversations about the adolescent's wishes, beliefs, values, preferences and goals. http://www.jpedhc.org/article/PIIS0891524509002107/abstract

From Media Watch dated 1 February 2010:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 22 January 2010 – **'Adolescents with life-threatening illnesses.'** Adolescents with life-threatening illnesses must rely on their parents, due to legal aspects of decision making, and they also face potential loss of peer interaction as they spend more time in hospitals and away from their friends. Adolescents may also be concerned with fertility, reproduction, and sexuality, issues that are often not addressed in palliative care programs. http://ajh.sagepub.com/cgi/content/abstract/1049909109358310v1



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

Legal ambiguities surround authority to make end-of-life decisions

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online article – 2 June 2011 – Should physicians have to seek consent from patients, substitute decision-makers or an independent tribunal in order to pull the plug on life-sustaining treatments they deem futile? An informal survey of Canadian case law indicates that courts have been all over the map on the issue, which has recently resurfaced in the headlines as part of a dispute between two physicians at the Sunnybrook Health Sciences Centre in Toronto, Ontario, and the family of a comatose man. The decision, which could radically alter how end-of-life decisions must be made in Ontario, pivots on the question of who should call the shots at end-of-life, an issue that has divided physicians, ethicists and legal minds for decades. The Ontario Court of Appeal is now deliberating whether to overturn a Superior Court ruling in April that would require doctors to obtain consent from patients or their substitute decision-makers to withdraw life-sustaining treatment, or failing that, take all disputed cases to the province's Consent & Capacity Board for mediation. The physicians believe that the lower court ruling would effectively force doctors to continue treatment as long as a patient or patient's surrogate desires, even in cases where it may not provide medical benefit or may even harm the patient, explains Mark Handelman, a Toronto lawyer intervening in the case and former adjudicator for the Consent & Capacity Board. "The fear is they'll end up with an intensive care unit full of people whose wishes, values or beliefs mean they have to be kept alive to suffer." Conversely, if ... [the] ... appeal is successful, it will set a major precedent that will allow Ontario doctors to make unilateral decisions about treatment at end-of-life, with or without consideration for patients' wishes, values or religious beliefs, Handelman argues. "I would be astonished to ever see another end-of-life case go before the Consent & Capacity Board. Why bother?"http://www.cmaj.ca/earlyreleases/2june11_consent-vogel.dtl

International Society of Advance Care Planning & End of Life Care Conference

BMJ SUPPORTIVE & PALLIATIVE CARE, 2011;1(1). There is increasing public and political interest in advance care planning ... as people recognise the importance of patient autonomy. For conference abstracts, scroll down to 'Abstracts from the International Society...' http://spcare.bmj.com/content/current

N.B. Ontario is the only province in Canada with a Consent & Capacity Board, which usually hears a case and issues a ruling in about a week.

Of related interest (i.e., similar legal challenges in Canada noted in previous issues of Media Watch):

- ONTARIO | *Toronto Star* – 20 March 2011 – **'Gravely ill man's wishes for life must be respected, panel finds.'** http://www.thestar.com/living/article/957080--gravely-ill-man-s-wishes-for-life-must-be-respected-panel-finds
- ONTARIO | Canadian Press – 17 May 2011 – **'Ontario appeal court to hear case about who decides when to remove life support.'** http://www.google.com/hostednews/canadianpress/article/ALeqM5gVR3jeMVS0u5K8xrifp8p4lpWTag?docId=6877046
- ONTARIO | *Toronto Star* – 25 October 2010 – **'Family, doctors battle over 'do not resuscitate' order.'** http://www.thestar.com/news/article/880422--family-doctors-battle-over-do-not-resuscitate-order
- ONTARIO | *Toronto Star* – 4 September 2010 – **'Lawsuit could set precedent about end-of-life decisions.'** http://www.thestar.com/news/gta/article/856741--lawsuit-could-set-precedent-about-end-of-life-decisions?bn=1
- MANITOBA | *National Post* – 29 March 2010 – **'Crisis in the ICU.'** http://www.nationalpost.com/news/canada/story.html?id=2738063

Isolated vs. rescued journey

The shift to early palliative care

CLINICAL JOURNAL OF ONCOLOGY NURSING, 2011;15(3):304-310. Clinical observations of communication between patients, families, and clinicians during chronic, serious, or terminal illness in a cancer care trajectory were examined for patterns and trends. Five communication characteristics were concluded, which informed a typology of illness journeys experienced by patients with cancer and their families. The isolated journey characterizes an illness path in which communication about terminal prognosis and end-of-life care options are not present; communication is restricted by a curative-only approach to diagnosis as well as the structure of medical care. The rescued journey signifies a transition between curative care (hospital narrative) to non-curative care (hospice narrative), challenging patients and their families with an awareness of dying. The rescued journey allows communication about prognosis and care options, establishes productive experiences through open awareness, and affords patients and families opportunities to experience end-of-life care preferences. Palliative care prior to hospice provides patients and families with an illness journey more readily characterized by open awareness and community, which facilitates a comforted journey. Nurses play a pivotal role in communicating about disease progression and plans of care. The typology presented can inform a structured communication curriculum for nurses and assist in the implementation of early palliative care. http://ons.metapress.com/content/7876255674w7mn73/?p=49f32a2111d44ad29246fe21462ec9ce&pi=9

Of related interest:

- *PRIMARY CARE CLINICS*, 2011;38(2):xi-xii. **"Dying with dignity."** This volume of the *Primary Care Clinics* serves as an ... primer for clinicians to use as a daily reference when called upon to assist patients and their families in the management of end-of-life conditions, from both a medical and a humanitarian standpoint. Introductory articles create a framework for clinicians to understand key terms and statistics relative to palliative and hospice care, as well a conceptual basis of the ethical considerations of such care. http://www.primarycare.theclinics.com/article/S0095-4543(11)00025-X/fulltext

  N.B. Journal contents page: http://www.primarycare.theclinics.com/current

Webcasting in home and hospice care services: Virtual communication in home care

HOME HEALTHCARE NURSE, 2011;29(6):337-341. There are many features in Ustream, but the most useful for home care and hospice service providers is its ability to broadcast sound and video to anyone with a broadband Internet connection, a chat room for users to interact during a presentation, and the ability to have a "co-host" or second person also broadcast simultaneously. http://journals.lww.com/homehealthcarenurseonline/Abstract/2011/06000/Webcasting_in_Home_and_Hospice_Care_Services_.2.aspx

Relieving existential suffering through palliative sedation: Discussion of an uneasy practice

JOURNAL OF ADVANCE NURSING | Online article – 1 June 2011 – The debates [on palliative sedation] have centred on ethical issues surrounding decisions to use sedation and on separating the intent of palliative sedation (relief of intolerable symptoms) from the intent of euthanasia (hastening death). There is lack of consensus in defining existential suffering. Consequently, there is limited understanding of how decisions are being made when using palliative sedation to treat intractable existential suffering. Given the confusion and uncertainty about ethical and clinical justifications for palliative sedation in treating existential suffering, the authors argue that a better understanding of the controversies and decision-making process is needed. Greater understanding is required to prevent palliative sedation from becoming a substitute for intensive treatment of this kind of suffering. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2648.2011.05711.x/abstract

Changing the conversation: How Americans talk, think and feel about aging

LONG TERM CARE & ASSISTED LIVING (U.S.) | OpEd – 1 June 2011 – In my 25 years as a physician, I've never heard anyone describe themselves as a "functionally impaired patient with chronic multiple conditions," a "long-term care recipient" or a "dual eligible." Yet these types of terms are used every day among healthcare professionals, policy wonks and advocates to describe the very people on whose behalf we work. The result of using this vernacular is that we talk at people rather than with them, effectively turning living, breathing human beings into obscure concepts. Dehumanizing the most human of processes – namely, growing older with health needs – breeds fear and apathy among the public at best, and at worst, alienation from a healthcare system that is perceived as too cold to care, too complicated to understand, and nearly impossible to navigate. http://www.mcknights.com/changing-the-conversation-how-americans-talk-think-and-feel-about-aging/article/204283/

Extract:

Almost as important as what words were used are the words that were not used: hospice, palliative, geriatric, advance, dependence, death, specific diseases, legal phrases (e.g., advance directives or durable power of attorney) or anything else with those Latin or Greek derivations so beloved by the medical and other professional communities.

Role recognition and changes to self-identity in family caregivers of people with advanced cancer: A qualitative study

SUPPORTIVE CARE IN CANCER | Online article – 25 May 2011 – Three dominant codes are presented. Caregivers [i.e., study participants] lacked role recognition, as they struggled to recognise their role existed, even though they took on extensive and challenging tasks. Caregivers reported substantial loss or changes to their self-identity: with some caregivers reporting not being able to stop thinking about caregiving and others having difficulty answering questions about themselves. Caregivers also demonstrated difficulty in taking a break: active caregivers did not consider taking a break, whereas bereaved caregivers retrospectively admitted needing a break but reported an inability to take one. Caregiving is complex and extensive. People who care for those with advanced cancer are in need of intervention to provide support and assistance to them in their role. However, this needs to be structured with consideration for how caregivers view their role. http://www.springerlink.com/content/10l4n6j2174m1h42/

Of related interest:

- *JOURNAL OF APPLIED GERONTOLOGY* | Online article – 25 May 2011 – **'Analysis and proposed model of family caregivers' relationships with home health providers and perceptions of the quality of formal services.'** This study explores family caregivers' accounts of relationships with home care nurses; findings inform a model of relationships and satisfaction with home health services. Findings highlighted the importance of the length, frequency, and continuity of contact, conversation, socializing, and sharing information. Participants were cognizant of their own and care recipients' roles in building relationship. A model links relationship preconditions, relational demonstrations, and perceived care quality and may be used to identify points of intervention. http://jag.sagepub.com/content/early/2011/05/25/0733464811408699.abstract

Media Watch posted on Palliative Care Network-e Website

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. http://www.pcn-e.com/community/pg/file/world/world/

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online article – Accessed 5 June 2011 – **'The question of public support for assisted suicide or euthanasia in Canada.'** In 1972, the Canadian Criminal Code was revised so that suicide was no longer a punishable offense, but assisted suicide and euthanasia identified as punishable by law. Developments since then have lead to the question of whether or not the public is supportive of legalization. Few public surveys have been conducted in Canada or other countries. The University of Alberta's Population Research Laboratory was asked to add questions to their annual telephone survey. Amazingly, 77.3% of all responders said yes to the question: Should dying adults be able to get help from others to end their life early? Specifically: 36.8% said yes, every competent adult should have this right; 40.6% said yes, but it should be allowed only in certain cases or situations, 22.7% said no, and 6.2% gave no answer. Albertans did not differ in their support for hastened death by past experience caring for a dying person, having had a friend/family member pass away, where they lived, gender, marital status, income, ethnicity and voting preferences. Four sub-groups were not as supportive (although 50%+ were still in support): religious people, older adults, those without high school completion, and those without a living will. Albertans are surprisingly open to hastened death, with this information needing to be taken into consideration for future developments in advanced care planning and end-of-life care. http://spcare.bmj.com/content/1/1/106.1.abstract

Worth Repeating

To the bitter end: Disparities in end-of-life care

JOURNAL OF HOSPITAL MARKETING & PUBLIC RELATIONS, 2008;18(2):167-185. Although technological advancements have provided the means to sustain life and provide care regardless of whether the treatment is appropriate and compassionate given the condition of the patient, bioethical, legal, and moral concerns related to disparities in care still arise. These concerns call into question the necessity to continue life-sustaining or palliative care treatments when patients and/or families are faced with end-of-life decisions. This study focuses on various historical, clinical cultural, and ethical issues that have placed this dilemma into a controversial public spectrum, by using case studies retrieved from referenced literature, which illustrate disparities in care at the end of life. http://www.informaworld.com/smpp/content~db=all~content=a903756473

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