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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Barriers to early referrals to palliative care: Scroll down to <u>Specialist Publications</u> and 'Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center' (p.10), published in the *Oncologist*.

Canada

Treat ailing elderly as patients not 'bed blockers'

ONTARIO | Toronto Star (OpEd) - 7 January 2011 - Ontario's hospitals are operating over their capacity. Nineteen thousand beds have been closed over the last 15 years. In Sudbury, patients sleep in broom closets. Ours is the most efficient hospital system in Canada – operating with \$260 fewer dollars per citizen, with the shortest lengths of stay and the fewest beds and staff per capita of any province. Successive governments in Ontario haven't had the courage to take on the doctors or the drug companies or the private care corporations, which are driving up healthcare spending. So most of the efficiencies have been made in the already efficient hospital sector, where a permanent revolution has been in effect for 20 years. with ongoing restructuring, downsizing and privatization. Now, war has been declared on the "bed blockers" so that another 5,000 beds can be closed. But the real problem is that too many hospital beds have been

closed. There aren't enough beds for all of the acutely ill people who need them. <u>http://www.thestar.com/opinion/editorialopini</u> on/article/917633--treat-ailing-elderly-aspatients-not-bed-blockers

Extract from Toronto Star OpEd

At 90 years old, with congestive heart failure, diabetes and arteriosclerosis, Alice MacPherson was given two months to live by her doctors. She needed palliative care so that she could die as peacefully as modern medicine will allow. A Windsor hospital threatened to bill her \$600 a day – they needed her bed and they wanted her out. There is no compassion and there is no empathy. The fact that MacPherson was dying didn't matter to the hospital or appear to matter to the Ministry of Health. What mattered was getting her out of hospital and into a nursing home or retirement home where, guaranteed, there is less care than needed in her last days.

The cost-effective argument for hospice palliative care services

NOVA SCOTIA | Chronicle-Herald (Halifax) – 4 January 2011 – The fact that Canadians seldom envision the end-of-life process does little to prevent it from occurring. However, our deathdenving culture accommodates government inaction regarding the provision of palliative care supports to Canadians in their last weeks of life; and the unhappy realization that the majority of us will die in an acute-care hospital bed meant for the living, not the dving. Senator Sharon Carstairs ... warns of a "tsunami of aging" that will undermine an already significantly inaccessible system of palliative care in Canada.¹ Beyond her assertion that the end of our lives should be viewed as important as our births, Ms. Carstairs presents a compelling argument on the costeffectiveness of palliative care programs, services supporting the physical, social, emotional and spiritual needs of patients and family members coping with advanced illness, death and bereavement. On average, each death affects five other individuals. The number of Canadians who report missing more than a month of work to care for a seriously ill loved one has grown proportionately to our aging population. This reduction in workplace productivity will continue to escalate as temporary or forced leaves of absences by caregivers mirror the climbing death rate. In addition to this economic shortfall, the process of dving in a hospital is made more costly and inefficient by hospital administrators more concerned with the implementation of a medical model of care rather than one that recognizes, and is responsive to, the growth of the population of elderly people with multiple chronic conditions. http://thechronicleherald.ca/Letters/1220128.html

1. *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*, June 2010. <u>http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare_e.asp</u>

N.B. Noted in Media Watch dated 14 June 2010.

National Assembly¹ Select Committee on Dying with Dignity

Dying with dignity hearings set to resume in Québec

QUÉBEC | CTV News (Montréal) – 3 January 2011 – Emotionally charged hearings into the controversial issues of dying with dignity and euthanasia are set to resume in Québec. The Select Committee on Dying with Dignity has been reviewing medical practices on euthanasia and end-of-life care, visiting 11 communities across Québec. They began hearings in September ... and are set to start new hearings again soon... Georges Buscemi, the president of the Québec Life Coalition, says there appears to have been some misunderstandings about what the debate has been about. "Let's not forget that the consultation underway in Québec is about dying with dignity. That means when you die, you can die painlessly, you can die surrounded by your loved ones," [says] Buscemi. "Talking about assisted suicide – allowing a doctor to kill a patient – is a whole other subject." http://montreal.ctv.ca/servlet/an/local/CTVNews/20110103/assisted-suicide-dying-dignity-110103/20110103/?hub=MontrealHome

1. The National Assembly of Québec (Assemblée nationale du Québec) is the legislative body of the Province of Québec.

<u>U.S.A.</u>

Costs vs. care: Dispute arises over state plan to cut hospice option

SOUTH CAROLINA | Independent Mail (Anderson) – 7 January 2011 – Upcoming Medicaid cuts that eliminate hospice care coverage for terminally ill adults could end up costing South Carolina more than it saves, hospice providers said this week. Advocates are warning state officials about potential fallout beyond the human toll on patients and families: Medicaid patients denied hospice care will seek medical attention elsewhere at a higher cost. State officials said they are aware of the economic risks and that they have no choice but to make immediate cuts to grapple with crippling budget shortfalls. http://www.independentmail.com/news/2011/jan/07/costs-vs-care-dispute-arises-over-state-plan-cut-h/

White House changes end-of-life Medicare rules

CBS NEWS | Online report - 5 January 2011 – Reversing a potentially controversial decision, the Obama administration will drop references to end-of-life counseling from the ground rules for Medicare's new annual check-up. The latest shift on the sensitive subject comes ahead of a vote next week in the new GOP [Grand Old (i.e., Republican)] led House to repeal President Barack Obama's landmark health care overhaul. The decision is not likely to have much impact on patients and doctors already discussing options for care in the last stages of life. For example, voluntary end-of-life planning is already covered as part of the "Welcome to Medicare" doctor visit, available to seniors within the first year of joining the program. The original House version of the overhaul legislation sought to expand coverage, allowing for discussions every few years. But the plan was dropped after Sarah Palin and other Republicans raised the specter of "death panels" deciding the fate of vulnerable seniors. Those charges were later debunked by several non-partisan fact-checking groups. End-oflife counseling unexpectedly surfaced again late last year in a Medicare regulation that spelled out what would be covered in a new annual checkup, or wellness visit, authorized by the health care law. End-of-life planning is already an accepted part of care for people facing terminal illness, and the administration's reversal is unlikely to have much impact on that. Longstanding federal

rules require hospital patients to be informed of their right to spell out in a living will or similar document their wishes about being kept alive by machinery if there's no hope for a cure. However, many doctors and public health advocates believe the government should take a more direct role encouraging people to plan ahead. They say it would save families the ordeal of having to make agonizing decisions when a loved one is incapacitated.<u>http://www.cbsnews.com/stori</u> es/2011/01/05/national/main7216133.shtml

Study: Blacks less likely to have living wills, medical directives

U.S.A. TODAY | Online report – 6 January 2011 – Nearly two-thirds of nursing home patients have advance directives, documents allowing people to make end of life decisions when they might not be able to speak for themselves, a government study shows. But the study reveals a significant gap between black and white patients with the documents.<u>http://www.usatoday.com/yourlife/heal</u> th/medical/2011-01-06-livingwills06 ST N.htm

Specialist Publications

Of particular interest:

'Calls for reform to the U.S. hospice system' (p.8), published in *Ageing International*.

- ESQUIRE MAGAZINE | Online article 4 January 2011 'Now this is what a 'death panel' looks like.' "It lets you make your own choice," says Barbara Aplin, shouldering an oxygen tank on her way to the lunch line here at the senior Community Center in Green Bay, Wisconsin. She is speaking not of her meal options in 2011 but of so-called "death panels," the more colloquial name for the new Medicare rule now paying doctors to counsel this 76-year-old ... and her fellow senior citizens about end-of-life care. If you listen to the new fear merchants from the right, the rule pushes seniors to opt out of medical treatment that might prolong their lives. But take an afternoon to listen to the actual grandmas, and you get a much different kind of scare. If her children don't listen to an end-of-life plan, Aplin says, "I'll come back to haunt them." Barb can rest easy, because that's the whole point of what the Sarah Palins and Tucker Carlsons of the world call "death panels." http://www.esquire.com/blogs/politics/death-panels-are-real-4718193
- MARYLAND | Baltimore Sun (OpEd) 3 January 2011 'Moral confusion at life's end.' "Death panel, "playing God" or "dying with dignity" are nice catch-phrases, but they do little to clarify the obstacles before us. A major problem is that we rely on several different moral guidelines. While helpful for everyday matters, they have shortcomings when applied to life-and-death issues. http://www.baltimoresun.com/news/opinion/oped/bs-ed-death-20110103,0,4939313.story

lowa law leaves terminally ill children little choice on where to die

IOWA | *The Independent* (Des Moines) – 4 January 2011 – For children dying from incurable cancer or other terminal illness, the end of life is supposed to be a time of intimacy surrounded by family and loved ones. But when parents or bystanders call 911 out of panic or for help to ease their child's suffering, they sometimes prompt a rescue process that is out of their control. The summoned EMS [Emergency Medical Service] workers must do everything possible to keep the child alive and get them to the nearest emergency room, even if that means going against family wishes and the physician's treatment plan, according to Dr. Paige Volk, a pediatric critical care physician at the University of Iowa Children's Hospital. While terminally ill adults can have advance directives from their doctors forbidding such interventions outside the hospital, a little-known Iowa law does not allow the same power to similarly situated minors and their parents. The law puts Iowa out of step with the ethical position of the nation's largest association of pediatricians and with an increasing number of states. <u>http://iowaindependent.com/49992/iowa-law-leaves-terminally-ill-children-little-choice-on-where-to-die</u>

Expressions of grief

Sidewalk shrines have 30 days

MASSACHUSETTS | *Telegram* (Worcester) – 4 January 2011 – Acknowledging it's a sensitive issue, the Department of Public Works & Parks will formalize a policy on sidewalk memorials that city officials say will help balance mourning for loved ones killed in accidents or crimes with public safety. About 40,000 people are killed in traffic accidents every year in the U.S., and the informal signs help personalize the victim and warn other drivers to be safe. However. the memorials sometimes pit families mourning victims against other families or officials with concerns about distracted driving or blocking the right-of-way. http://www.telegram.com/article/20110104/N EWS/101040403/-1/NEWS06

Of related interest:

 WASHINGTON DC | Washington Times

 4 January 2011 – 'Grief, loss, and the search for meaning.' Some people say that serious illnesses have no meaning other than the fact that they occur. This kind of observation is frustrating and annoying, mainly because most human beings find meaninglessness maddening. Declaring a serious personal event meaningless implies that expending further thought and emotion is fruitless. It's a way of using logic to protect oneself from pain. Yet even facing terminal illness, a few

(Cont. next column)

inquisitive, courageous people prefer to use their logical ability more creatively than that. They also choose to explore their emotions rather than squash them. <u>http://communities.washingtontimes.com</u> /neighborhood/stagesgrief/2011/jan/4/grief-loss-and-searchmeaning/

Media Watch Online

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

Canada

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network: <u>http://www.hnhbhpc.net/Resources/UsefulLinks/M</u> ediaWatch/tabid/97/Default.aspx

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

Ontario | Mississauga Halton Palliative Care Network:

http://www.mhpcn.ca/Physicians/resources.htm (Scroll down to 'Newsletters/Media Updates')

U.S.A.

Prison Terminal: http://www.prisonterminal.com/news%20media%2 0watch.html

International

Global | Palliative Care Network Community: http://www.pcne.com/community/search/?tag=Media+Watch

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

CONNECTICUT | Hartford Courant – 7 January 2011 – 'In alleged assisted suicide, a question of ethics.' Stephen Latham can understand why Bruce Brodigan might have been motivated to help his father end his life, as police have alleged, but said George D. Brodigan's suicide raises ethical questions. Helping someone commit suicide can be a selfish act, or it can be done out of love, said Latham, a medical ethicist at Yale University. And helping someone with a mentally disabling condition like Alzheimer's disease, as in George Brodigan's death, creates those complex ethical issues. http://articles.courant.com/2011-01-07/news/hc-west-hartford-brodigan-0108-20110107 1 suicide-note-father-end-final-exit

International

When a death wish is desirable: End-of-life decisions

THE AUSTRALIAN | Online OpEd - 8 January 2011 – It's upsetting to see elderly patients in their 80s and 90s - most with no chance of recovery – plugged in to modern technology in intensive care beds for which there is growing demand. The Geelong Hospital senior intensive care doctor put it succinctly when he said: "We can prolong life but [for these people] we cannot restore health." At the risk of appearing to be unfeeling, there's also the issue of cost. Not surprisingly, hospital costs increase proportionately with proximity to death, although it's not as simple as that. Lesley Russell of the Menzies Centre for Health Policy at the University of Sydney and the Centre for American Progress in Washington, DC, reported in early 2009 that in Australia in 2007, end-of-life hospital care averaged about \$13,500 per person, with about 40% spent in the last month of life. The biggest costs are incurred caring for people aged 65 to 74. As people age further, hospital costs fall, so for people aged 95 or older hospital costs are less than half those of their younger counterparts. This is because a large majority of people aged 95 or more die outside of hospitals. A critical cost consideration, however, is the estimate that about 10% of all health costs in Australia go to providing procedures that people nearing the end of life don't want. While this shouldn't be seen solely as an economic issue, extending inappropriate care to one person generally delays or denies care to another. It's particularly difficult to accept this when many patients

don't want the treatment they're getting. Any ethical assessment of these issues must therefore take this reality into account. People plan for so much in life but when it comes to addressing issues of end-of-life medical treatment and care, they shy away from doing so, either because they don't know how or because they'd rather put it off. But putting it off often results in treatment or heroic medical enterprise, which, given a choice, the patient probably wouldn't want. http://www.theaustralian.com.au/news/health -science/when-a-death-wish-is-desirableend-of-life-decisions/story-e6frg8y6-1225983238944

Support steadfast for death to ease pain

AUSTRALIA (NEW SOUTH WALES) | Sydney Morning Herald – 6 January 2011 – Three out of four Australians believe voluntary euthanasia should be legal, a poll has found. But despite levels of endorsement that have hovered between 75-85% for many years, pro-euthanasia reformers admit to having been consistently outgunned by their opponents, resulting in five failed attempts to pass legislation in two years. The latest poll by The Australia Institute found 75% of people agreed that if someone with a terminal illness who is experiencing unrelievable suffering asks to die, a doctor should be allowed to assist them to die. Thirteen per cent did not agree and 12% were not sure. http://www.smh.com.au/national/supportsteadfast-for-death-to-ease-pain-20110105-

<u>19gau.html</u>

A model to treat the dying that could be rolled out in other nations

INDIA | BBC 4 (Crossing Continents) – 6 January 2011 – It's estimated that nearly one million Indians with conditions like cancer die in acute, unnecessary pain because of the lack of palliative care. Restrictions on morphine prescription are being lifted, but too slowly. One of the most sophisticated systems of palliative care in the developing world has been established in the Indian state of Kerala. The grassroots movement to create a much-valued and effective palliative care system in Kerala has been called a silent revolution. Every week, thousands of volunteers across the state give up their time to go and tend to those who are dying. They may cook food, help with chores, or simply provide a listening ear. Hundreds of thousands more people in Kerala belong to Palliative Care Societies. They donate money regularly ... to help support this kind of outreach. The hope is that people will not die alone, and in pain, without any support. Kerala ... has more palliative care centres than the rest of the country put together. Is this is a model to treat the dying that could be rolled out in other nations, as well as other parts of India? http://www.bbc.co.uk/iplayer/episode/b00wr9v8/Crossing Continents Palliative Care in India/

From Media Watch dated 2 August 2010:

- Times of India | Online report 16 July 2010 'India worst in end-of-life care.' India doesn't just have a poor quality of life, as reflected in its poor human development index, it also has a particularly poor 'quality of death.' That's the depressing message from a new index developed by the Economist Intelligence Unit [EIU] to measure end-of-life care services in 40 countries.¹ http://timesofindia.indiatimes.com/India/India-worst-in-end-of-life-care/articleshow/6174380.cms
 - 1. The Quality of Death: Ranking End of-life-care Across the World,EIU, July 2010. http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf

N.B. The EIU study was commissioned by the Lien Foundation: <u>http://www.lienfoundation.org/</u>, and publication of the Quality of Death Index was reported on in detail in the editions of Media Watch dated 26 July (p.2) and 19 July 2010 (pp.1,2 & 3).

Let's talk about death, say charities

U.K. | *The Guardian* – 5 January 2011 – When Ben Kypreos's mother was diagnosed with lung cancer, the family was unaware that she would live for only another six weeks. "The initial diagnosis was a huge shock," he recalls. "We hadn't even begun to start talking about the end of her life." Treatments were being discussed and Maggie Kypreos had not made any plans for her death, he says. According to the National Centre for Social Research, for 45% of people death feels a long way off. "Unless we can start conversations about dying, we end up with people receiving unwanted medical attention or leaving behind an emotional mess for their families who feel they weren't able to fully support the dying person," says Hilary Fisher, director of Dying Matters, an umbrella group set up by the National Coalition for Palliative Care to promote public awareness of dying, death and bereavement. "The taboo surrounding talking about dying directly impacts on the quality of end-of-life care." It is not just a problem for individuals, she says, but also health professionals, who can be reluctant to bring the subject up for fear of upsetting patients and their families. http://www.guardian.co.uk/society/2011/jan/05/lets-talk-about-death-say-charities



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.

Three-step process proposed to request withdrawal of life support

TAIWAN | Focus Taiwan – 4 January 2011 – A legislative committee approved amendments to a law ... that would allow the next of kin of terminally ill, non-cognitive patients to jointly decide to end life support. Amendments to the Hospice & Palliative Care Act ... will provide the basis for a three-phase process of carrying out such a decision. First, family members must make the request, then an ethics committee would be required to review the request and finally two medical doctors must determine that the patient would have no chance of surviving for more than 2-4 weeks. <u>http://focustaiwan.tw/ShowNews/WebNews_Detail.aspx?Type=aALL&ID=201101040030</u>

From Media Watch dated 3 January 2011:

 TA/WAN TODAY | Online report – 31 December 2010 – 'Taiwan's Legislature mulls National Health Insurance card living will bill.' Taiwan's National Health Insurance cards may soon be legally recognized as living wills if amendments to the Hospice Palliative Care Act are passed by the Legislature. <u>http://www.taiwantoday.tw/ct.asp?xltem=140881&ctNode=445</u>

Record deaths in Japan spurs new businesses, like hotel for the dead

JAPAN | ABC World News (U.S.) – 3 January 2011 – The Liss Center stands three stories high, sandwiched between large warehouses on the outskirts of Tokyo. A flickering sign greets visitors in the parking lot, and the hotel's "guests" are welcomed through large metal doors. The antiseptic white walls and smell of disinfectants don't exactly scream business hotel, but owner Nyokai Matsushima affectionately calls this "a business hotel for the dead." The Liss Center in the Shinkiba neighborhood acts as a temporary morgue. On this day there are 37 guests, or bodies. Each corpse is tagged with a bar code to avoid mix-ups. The bodies are carefully placed in one large refrigerator, and the ceilings come with antibacterial lights attached to avoid any decay. "Guests" stay for 7,350 yen a night – roughly \$88, while bereaved families can opt to seek out advice on funeral services from hotel staff. The center is the first business venture for the long-time Buddhist monk and is intended to give Japanese families a place to hold bodies while dealing with the grief and pressure of a funeral. "I was inspired to build this hotel, about 14 years ago," Matsushima says. "I wanted to create a space where the deceased could come to rest, without any pressure from funeral companies." http://abcnews.go.com/Business/record-number-deaths-spur-japanese-funeral-industry/story?id=12526337

Of related interest:

 U.K. | BBC Radio 4 Today – 3 January 2011 – 'The business of death.' Screening an advert for funeral services on television would, ten years ago, have been unthinkable for a business model defined by discretion. But the funeral sector, it seems, doesn't want to hide any more. From television advertising campaigns from Cooperative Funeral Care, to so called "eco coffin" makers marketing themselves in local newspapers, this is an industry on the move. All be it in a slow, dignified sort of a way. <u>http://news.bbc.co.uk/today/hi/today/newsid 9324000/9324262.stm</u>

Intervening on a family's private grief

Post-mortem rates in England & Wales 'should be cut'

U.K. | BBC News – 3 January 2011 – The number of post-mortem examinations in England & Wales could be cut by 60% if the system in Scotland was used. Professor Derrick Pounder said the rate of 110,000 coroner autopsies per 500,000 deaths could not be justified. Writing in the *Journal of the Royal Society of Medicine*,¹ he said more use of external examinations should be used to determine cause of death. Scotland's autopsy rate is 6% compared to 22% in England & Wales. Professor Pounder said the state intervened on a family's private grief by ordering a full post-mortem examination in too many cases. External examinations were also a more cost-effective method of identifying cause of death, he said. <u>http://www.bbc.co.uk/news/uk-12109847</u>

Cont.

1. Journal of the Royal Society of Medicine, 2011;104(1):19-24. 'How can we reduce the number of coroner autopsies? Lessons from Scotland and the Dundee initiative.' In the authors' view external examinations are not only cost-effective but also a necessary element in any death investigative system which wishes to strike an appropriate balance between intrusion by the state and the rights of the bereaved. http://jrsm.rsmjournals.com/cgi/content/abstract/104/1/19

Assisted (or facilitated) death

Representative sample of recent news media coverage:

SWISSINFO.CH | Online report – 4 January 2011 – 'Case puts assisted suicide at a crossroads.' The acquittal of a doctor accused of euthanasia has rekindled the debate on assisted suicide in Switzerland. A regional criminal court in Boudry, canton Neuchâtel, ruled in December that the doctor had no choice when she took the final step to end the life of a terminally ill patient. Direct active euthanasia is illegal in Switzerland but assisted suicide and passive euthanasia are not.<u>http://www.swissinfo.ch/eng/politics/Case_puts_assisted_suicide_at_a_crossroads.html?cid=29_157532</u>

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

Calls for reform to the U.S. hospice system

AGEING INTERNATIONAL | Online article – 30 December 2010 – The purpose of this paper is to provide a historical perspective of the hospice system within the U.S. ... [and discuss] ... current trends ... and provides a platform for discussion about the future of the system in terms of policy standards. The more than 30 year history of hospice in the U.S. has experienced many changes. Originally organized as non-profit entities, hospices became Medicare funded in the 1980s and has seen substantial growth in the number of for-profit entities. Hospice has moved from being seen as a "place to go die" to being viewed as a viable option for long-term care near the end of life. Changes in the hospice payment system from a *per diem* reimbursement system and calls for quality measures are at the forefront of the current system and the major issues that the system faces in the future. http://www.springerlink.com/content/2302h48572387271/

Of related interest:

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online article 4 January 2011

 'Perceptions about hospice from a community-based pilot study: Lessons and findings.' Research investigating the knowledge and attitudes of diverse older adults about hospice care and end-of-life issues is needed to expand service utilization. Although recruitment efforts [for this study] resulted in a relatively homogenous sample, findings suggest a lack of knowledge about whether hospice is covered by Medicare, Medicaid, or private insurance. Perceptions of the expense of hospice, however, were not associated with knowledge of coverage. Respondents generally agreed that hospice is important and would recommend its services for their family members. http://ajh.sagepub.com/content/early/2011/01/04/104909110394339.abstract
- JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2011;13(1):41-46. 'Will patients want hospice or palliative care if they do not know what it is?' Knowledge of hospice care was lower among African Americans than whites and among those with limited education. Knowledge of palliative care followed the same pattern, but even fewer people were aware of or could define those services. Improved awareness of hospice and palliative care is a first step toward reducing disparities in utilization of important and useful services for persons with life-limiting illnesses. Lack of awareness may limit access by cancer patients to needed hospice and palliative care. http://journals.lww.com/jhpn/Abstract/2011/01000/Will Patients Want Hospice or Palliative Care _if.9.aspx

Development of the Korean hospice system

Comparison of the hospice systems in the U.S., Japan and Taiwan

ASIAN NURSING RESEARCH, 2010;4(4):163-173. To assist in the development of the Korean hospice system, the Korean government supported the present study comparing the hospice systems of three countries, U.S., Japan, and Taiwan. The hospice system was evaluated by comparing hospice management systems and hospice cost systems. The comparison of the hospice management system included five items of hospice infra structures and four items of hospice services. Based on the comparison of three countries, the most interesting thing was that home hospice care accounted for more than 90% of all hospice services in the U.S. and Taiwan. The results of this study will aid the countries that are in the process of developing a hospice system including Korea, which has been implementing a pilot project only for hospital hospice services. <u>http://www.asian-nursingresearch.com/article/S1976-1317(11)60001-7/abstract</u>

World-wide literature survey on geriatric palliative medicine

EUROPEAN GERIATRIC MEDICINE | Online article – 28 December 2010 – Searches vielded 5075 records; 404 individual papers were included. Provenance: North America 43.3%. Northern Europe 5.5%, British Isles 17.8%, Western Europe 14.4%, Eastern Europe 1%, Southern Europe 6.2%, Japan and Australia 7.15%, other 4.7%. Eighty papers per year were published in 178 different periodicals. Type of studies: narrative reviews 12.1%, guidelines 4.5%, systematic reviews 3.2%, experimental studies 3.5%, expert opinions 17.6%, descriptive studies 29.0%, and observational studies 30.2%. Study objectives: intervention studies 47.8%, epidemiological studies 18.1%, and diagnostic studies 6.4%; 5.4% combined different objectives and 22.3% investigated other aspects of care. Disease category: advanced dementia 22.5%, cancer 21%, organ failure 12.1%, miscellaneous 44.3%. Forty-four topics were identified, the main ones being: end-of-life, psychology/spirituality, ethics, pain, age/ageism, symptom management, function/falls, organisation of care, nursing homes, palliative care, prescribing issues, guality, nursing, and education. As experimental data are lacking, clinicians and decision-makers must look to observational, descriptive and qualitative research which, in some cases, provides useful evidence. http://www.sciencedirect.com/science? ob=ArticleURL& udi=B9870-51TN1T9-1& user=10& coverDate=12%2F28%2F2010& rdoc=1& fmt=high& orig=search& origin=searc h& sort=d& docanchor=&view=c& acct=C000050221& version=1& urlVersion=0& userid=10& md5=e65a1642b3c2a556162a29262fc8fe64&searchtype=a

Unmeasured costs of a child's death: Perceived financial burden, work disruptions, and economic coping strategies used by American and Australian families who lost children to cancer

JOURNAL OF CLINICAL ONCOLOGY | Online article – 4 January 2011 – The authors describe the financial hardship, work disruptions, income loss, and coping strategies of families who lost children to cancer. Thirty-four (24%) of 141 families from U.S. centers and 34 (39%) of 88 families from the Australian center reported a great deal of financial hardship resulting from their children's illness. Work disruptions were substantial (84% in the U.S., 88% in Australia). Australian families were more likely to report quitting a job (49% in Australia v. 35% in the U.S.). Sixty percent of families lost more than 10% of their annual income as a result of work disruptions. Australians were more likely to lose more than 40% of their income (34% in Australia v. 19% in the U.S.). Poor families experienced the greatest income loss. After accounting for income loss, 16% of American and 22% of Australian families dropped below the poverty line. Financial hardship was associated with poverty and income loss in all centers. Fundraising was the most common financial coping strategy (52% in the U.S. v. 33% in Australia), followed by reduced spending. Significant household-level financial effects of a child's death as a result of cancer were observed, especially for poor families. Interventions aimed at reducing the effects of income loss may ease financial distress. <u>http://jco.ascopubs.org/content/early/2011/01/04/JCO.2009.27.8960.abstract</u>

Patients' and surrogates' decision-making characteristics: Withdrawing, withholding, and continuing life-sustaining treatments

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2011;13(1):16-28. Spiraling healthcare costs and propensity to prolong life in the chronically and critically ill have spurred national debate [in the U.S.] of end-of-life care in the older adult population. Given the challenges associated with longevity, evaluation of current care practices and research are needed to determine best practice to improve communication for a diverse group with differences in culture, ethnicity, education, language, and family systems that influence decision making at end-of-life. Awareness of patients' and surrogates' decision-making characteristics and communication. http://journals.lww.com/jhpn/Abstract/2011/01000/Patients_and_Surrogates_Decision_Making. 6.aspx

To cry or not to cry: Physicians and emotions at the bedside

MINNESOTA MEDICINE | Online article – January 2011 – During end-of-life discussions with a long-time patient, it is not uncommon for a physician to shed tears. Doing so allows them to express their sadness for the patient's and family's current and future losses. Being able to express such emotion can provide relief for physicians and convey empathy to the patient and family. The challenge for physicians is being able to express how they feel while still being an objective advocate for the patient. This article describes the findings of a survey of blood and marrow transplant physicians who were asked whether it is OK to cry in front of patients. http://www.minnesotamedicine.com/CurrentIssue/tabid/3625/Default.aspx

N.B. Article was miss titled at the time it was accessed 4 January 2011

Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center

ONCOLOGIST | Online article – 6 January 2011 – The authors previously found that the term "palliative care" was perceived by oncology professionals as a barrier to early patient referral. [The findings of this study indicate that] ... the name change to supportive care was associated with more inpatient referrals and earlier referrals in the outpatient setting. The outpatient setting facilitates earlier access to supportive/palliative care and should be established in more centers. http://theoncologist.alphamedpress.org/future/16.1.dtl

From Media Watch dated 5 April 2010:

- CANADIAN JOURNAL OF CARDIOLOGY, 2010;26(3):135-141. 'End-of-life planning in heart failure: It should be the end of the beginning. Recommendations are made [in the Canadian Heart Health Strategy & Action Plan¹] central to which is the need to reframe CVD [cardiovascular disease] as a condition ideally suited to a chronic disease management approach. Replacement of the term 'palliative care' with the term 'end-of-life planning and care' is proposed. http://www.pulsus.com/journals/abstract.jsp?sCurrPg=abstract&jnlKy=1&atlKy=9419&isuKy=907&is Art=t&fromfold=Current Issue
 - 1. Canadian Heart Health Strategy & Action Plan website: http://www.chhs-scsc.ca/
- PROGRESS IN PALLIATIVE CARE, 2010;18(2):66-71. 'Language, discourse and meaning in palliative medicine.' Palliative care language can separate or confuse people about the reality of palliative care and be exclusionary to other specialties who work outside the field. Great care is needed in choosing words to describe palliative care, since words incarnate the service. http://docserver.ingentaconnect.com/deliver/connect/maney/09699260/v18n2/s1.pdf?expires=1270 218327&id=55974319&titleid=6597&accname=Guest+User&checksum=FF4A51377AAAA766A31 B01A323408874

Worth Repeating

Life and death in old age

Do not cast me away when I am old

THE GERONTOLOGIST, 2007;47(4):559-565. This essay discusses three books, each of which provides a particular lens on death in old age, in this case from medicine and public policy, bioethics, and literature. Sick to Death and Not Going to Take It Anymore: Reforming Health Care for the Last Years of Life presents the perspective of a geriatrician, policy analyst, and ethicist whose practice and research has for decades dealt with the clinical nuances of how and where people die in America – and how doctors and health care providers can make death better. The book is propelled by the author's outrage that we cannot provide better endings, and that so many people die in pain, poverty, and loneliness, as victims of the lack of a reliable care system. She makes a convincing case that the problems are solvable. "Nothing is in the way except habit and inattention," she writes. Taking Care: Ethical Caregiving in Our Aging Society is a report issued by the President's Council on Bioethics. Its express purposes were to "provide a humanly rich account of the caregiving dilemmas - social, familial, and personal - and to offer some important ethical guidelines for the care of persons who can no longer take care of themselves." Everyman is a stunning fictional masterpiece about the aging, health, and death terror of an ordinary person who is experiencing the repeated assaults of serious illness, and living with the specter of looming death. http://gerontologist.oxfordjournals.org/content/47/4/559.full

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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.

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