Media Watch...

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

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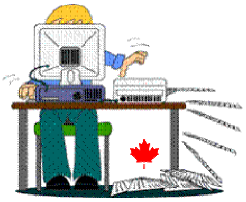


Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013 ©

Compiled & Annotated by Barry R. Ashpole

Effecting change in the illness experience: Scroll down to Specialist Publications and 'Dignity in care: Time to take action' (p.12), in *Journal of Pain & Symptom Management.*

Canada

Future Care for Canadian Seniors – Why it Matters

CONFERENCE BOARD OF CANADA | Online – 9 October 2013 – To provide for the care needs of today's and tomorrow's seniors, Canada must invest its increasingly scarce health dollars in the right type and mix of services. This primer provides an overview of the landscape of care and services outside of hospitals that support aging Canadians, along with a discussion of why it is important to look toward the future of care for Canadian seniors. 'Future Care for Canadian Seniors...' provides information on the numbers and life expectancy of the over-55 population between 2013 and 2030, their health conditions and medical requirements, living arrangements, and out-of-institution support systems, including hospice or home-based palliative care [see side bar, right]. http://m.news1130.com/files/2013/10/14-125_FutureCareSeniors.pdf

Extract from Conference Board of Canada primer

Hospice (residential) or home-based palliative care services provide support for Canadians as they approach the end of life. The Canadian Hospice Palliative Care Association suggests that a palliative care approach early in the stages of disease, integrated with chronic disease management, is very beneficial to those with chronic life-threatening conditions. The association reports that somewhere between 16% and 30% of Canadians have access to palliative care services, and they typically receive that care only in the final days or weeks of life. Current priorities are to improve Canadians' advanced care planning and goal setting regarding care. These actions help to ensure that individual preferences for care are respected, even when a person is no longer able to express his or her choices.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 11 October 2013 – **'Majority of Canadians approve of assisted suicide: Poll.'** A solid majority of Canadians approve of euthanasia, putting public opinion firmly on one side of the debate as it gains traction in the courts and the political sphere, a recent Environics poll suggests. http://www.theglobeandmail.com/news/national/majority-of-canadians-approve-of-assisted-suicide-poll/article14819642/

Cont.

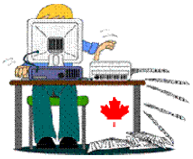
- BRITISH COLUMBIA | CBC News (Vancouver) – 10 October 2013 – **'Doctor-assisted suicide ban upheld in B.C.'** The B.C. Court of Appeal, in a split decision, has affirmed the law against assisted suicide, in a controversial and historic right-to-die case. Last year, ALS patient Gloria Taylor of Kelowna won a landmark ruling when a B.C. Supreme Court judge struck down Canada's law that made doctor-assisted suicide illegal. The judge concluded the Criminal Code provisions that prohibit assisted suicide violate the Charter of Rights & Freedoms. But the federal government appealed that ruling, saying the law protects vulnerable people. Taylor has since died from her degenerative neurological disease, more commonly known as Lou Gehrig's disease. Regardless of [the latest] ruling, many observers expect the case will end up at the Supreme Court of Canada, which ruled against physician-assisted suicide two decades ago in a landmark case involving another B.C. resident, Sue Rodriguez. http://www.cbc.ca/news/canada/british-columbia/doctor-assisted-suicide-ban-upheld-in-b-c-1.1958888

- QUEBEC | *The Montreal Gazette* (OpEd) – 10 October 2013 – **'Palliative-care providers oppose Bill 52, Quebec should listen.'** If we were to build a bridge and 90% of the engineers felt the design was dangerous, there would be a public outcry. Why is there no such outcry in Quebec in response to Bill 52, which the great majority of palliative-care providers oppose? Bill 52, Quebec's proposed legislation on medically assisted death, makes the following dangerous assertion: "End-of-life care means palliative care provided to persons at the end of their lives, including terminal palliative sedation and medical aid in dying." The bill, as proposed, unilaterally and without consultation with palliative-care specialists, redefines the meaning of palliative care. It proposes end-of-life care that is contrary to the internationally defined goals of palliative care. This is dangerous, as it will harm the provision of palliative-care services. http://www.montrealgazette.com/health/Palliative+care+providers+oppose+Bill+Quebec+should+listen/9022317/story.html

- SASKATCHEWAN | *The Star-Phoenix* (Saskatoon) – 9 October 2013 – **'Saskatchewan won't push euthanasia debate.'** Health Minister Dustin Duncan says he doesn't plan to advance the discussion over physician-assisted suicide, but he is watching what happens with the issue ... in Quebec. "I think the debate probably is already taking place in the public. That's certainly the perspective of other health ministers from across the country – that, by and large, it's not so much the legislatures, other than in Quebec, that are really leading the charge on having a debate across Canada. It's really Canadians that are raising this as an issue," he said. The provincial government hasn't debated the issue or pursued a clear policy on the subject... http://www.thestarphoenix.com/health/Sask+push+euthanasia+debate/9014796/story.html

  Noted in Media Watch, 7 October 2013, #326 (p.2):

  - *THE GLOBE & MAIL* | Online – 4 October 2013 – **'Ottawa leaves right-to-die debate to provinces.'** The federal government will not legalize euthanasia, leaving the matter to the provinces – and possibly the courts – to sort out. Federal Health Minister Rona Ambrose [recently] discussed assisted suicide with her provincial counterparts, including a proposal by Québec's Réjean Hébert [Bill 52] that would allow physicians to help terminally ill patients die in certain circumstances. http://www.theglobeandmail.com/news/national/health-minister-urges-legislatures-to-discuss-assisted-suicide/article14707199/



Barry R. Ashpole

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

U.S.A.

How long do you really want to live?

FORBES | Online – 11 October 2013 – Some of the nation's brightest minds have declared an all-out war against aging. From Google's campus to university labs to government think tanks, researchers claim babies born this year should live up to 120 years and, long before today's infants mature, some readily achievable changes in health care will have produced millions of sharp, active and healthy centenarians. There's just one problem: It's not entirely clear most Americans want to live to 120 – or much past 90, for that matter. The Pew Research Center ... asked more than 2,000 U.S. adults about their desire to live longer, as well as their hopes for enhanced life expectancy and medical services.[1] Only 38% of respondents said they would be willing to undergo treatments to extend their lives to 120 or beyond; 56% said they would not, although two-thirds said they believed most other people would. Most Americans, though, do expect to live longer than the current average U.S. life expectancy of 79. Asked how long they thought they would live, 69% stated an age between 79 and 100, with 90 being the median. In general, respondents to the survey were hopeful about medical advances to address cancer and other potentially fatal conditions. But they were deeply skeptical about life extension research. http://www.forbes.com/sites/nextavenue/2013/10/11/how-long-do-you-really-want-to-live/

Specialist Publications

'Health care utilization by patients whose care is managed by a primary palliative care clinic' (p.11), in *Journal of Hospice & Palliative Nursing.*

'Current state of psychiatric involvement on palliative care consult services: Results of a [U.S.] national survey' (p.12), in *Journal of Pain & Symptom Management.*

1. 'Living to 120 and Beyond: Americans' Views on Aging, Medical Advances and Radical Life Extension,' Pew Research, August 2013. http://www.pewforum.org/2013/08/06/living-to-120-and-beyond-americans-views-on-aging-medical-advances-and-radical-life-extension/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MISSISSIPPI | WDAM TV News (Moselle) – 10 October 2013 – **'Opinions on physician-assisted suicide sharply divided, poll shows.'** A poll from Gallup shows that Americans' support for physician-assisted suicide changes radically depending on whether or not "suicide" is used in the question's wording.[1] When asked if the doctor of a patient with an incurable disease should be allowed "to assist the patient to commit suicide" at the patient's request, 51% of Americans said it should be permitted. However, when the question was rephrased to ask if the doctor should be allowed "to end the patient's life by some painless means" at the patient and their family's request, support shot up to 70%. Yet another Gallup poll shows a divide in perception of the morality of aid in dying; 45% of Americans find it morally acceptable, while 48% say it is morally wrong.[2] http://www.wdam.com/story/23173532/opinions-on-physician-assisted-suicide-sharply-divided-poll-shows

  1. 'U.S. support for euthanasia hinges on how it's described,' Gallup, May 2013. [Noted in Media Watch, 3 June 2013, #308 (p.5)] http://www.gallup.com/poll/162815/support-euthanasia-hinges-described.aspx

  2. 'Doctor-assisted suicide is moral issue dividing Americans most,' Gallup National Values & Beliefs Poll, 31 May 2011. [Noted in Media Watch, 6 June 2011, #204 (p.3)] http://www.gallup.com/poll/147842/doctor-assisted-suicide-moral-issue-dividing-americans.aspx

International

End-of-life care in Japan

81% don't want life-prolonging treatments

JAPAN | *The Japan News* – 13 October 2013 – More than 80% of [3,000] people surveyed ... said they would not want to receive life-prolonging treatments in the terminal phase of an illness. Results ... show that many people want to face the final stage of their life in a natural way, part of a trend of people making preparations for death while they are still fairly healthy. http://the-japan-news.com/news/article/0000719262

About 3,600 people in Armenia need daily palliative care

ARMENIA | ARKA News Agency – 11 October 2013 – About 3,600 people in Armenia need daily palliative care, Hrant Karapetyam, head of the National Palliative Care Center of the National Cancer Center, told reporters. Armenia has now four pilot palliative care centers, which can treat up to 15 people a month. Two of them are located in medical institutions of Yerevan and the other two are in Ararat and Lori regions. In addition, the National Cancer Centre has a palliative care center, which was able to treat only 57 people in one year. These centers were opened in March this year as part of palliative care concept developed in 2012. The centers will conduct various studies ... and the findings will be used by experts to develop specific proposals for government funding. To date, a day's palliative care is worth 20 thousand drams (about $50). http://arka.am/en/news/society/about_3_600_people_in_armenia_need_daily_palliative_care/

Specialist Publications

'Survey of controversial issues of end-of-life treatment decisions in Korea: Similarities and discrepancies between healthcare professionals and the general public' (p.9), in *Critical Care.*

'Bridging the gaps in palliative care bereavement support: An international perspective' (p.9), in *Death Studies.*

'Attitudes of Polish physicians and medical students toward breaking bad news, euthanasia and morphine administration in cancer patients' (p.14), in *Journal of Cancer Education.*

'Attitudes of nursing staff towards involvement in medical end-of-life decisions: A [Dutch] national survey study' (p.10), in *Patient Education & Counseling.*

'Analysis of current conditions concerning development of palliative care in three selected countries of the former Eastern Bloc' (p.13), in *Polski Merkuriusz Lekarski.*

Media Watch posted on Palliative Care Network-e Website

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

Beckton's Richard House study reveals lack of awareness about hospice

U.K. (ENGLAND) | *The Newham Recorder* – 11 October 2013 – A survey ... has shown that there is a lack of awareness about such organisations. The study, carried out by Richard House Children's Hospice, showed more than 60% of those asked believed there were twelve or less children's hospices in the U.K., while there are in fact 42. This compares with 61% who correctly identified the total number of hospices (adults and children combined), indicating there is more understanding of the prevalence of hospices supporting adults than children in the U.K. http://www.newhamrecorder.co.uk/news/beckton_s_richard_house_study_reveals_lack_of_awareness_about_hospice_1_2875853

End-of-life care in India

Palliative care in Kerala not so balmy

INDIA (KERALA) | *The New India Times* (Chennai) – 9 October 2013 – By formulating a palliative care policy in 2008, Kerala had become a model for the rest of the country. But since then, it has done little to infuse the benefits to the deserving patients. Barring small projects initiated by the National Rural Health Mission in palliative care, the government hospitals do not have exclusive units for the same, a promise unfulfilled by the government. Though the local bodies submit projects in this regard, inadequate resources and lack of expertise prevents them from realising the full potential. The role played by family is also important. But the team appointed by the local bodies comprising a health inspector, an Asha [accredited social health activists] worker, trained Auxiliary Nurse Midwife, and a panchayat [the local self-government] member are hardly given any training. Surprisingly, the doctor in the Primary Health Centre, who is in charge of the patients is not part of the team. Hence, the element of immediacy is absent in the services offered... The doctors cannot prescribe on the spot treatments or medications, says Dr. Jose Babu, Medical Officer, Alpha Pain Clinic. http://newindianexpress.com/states/kerala/Palliative-care-in-Kerala-not-so-balmy/2013/10/09/article1826405.ece

Of related interest:

- INDIA (KERALA | *The Deccan Chronicle* (Secunderabad) – 13 October 2013 – **'Big strides in palliative care.'** The Pain and Palliative Care Society (PPCS), which started functioning from a single room at the Medical College Hospital here, with just two volunteers in 1993, has today become the backbone of the pain and palliative movement in the state. Now lauded as a "world model" in ensuring better care for terminally ill patients, the PPCS and its active arm, the Neighborhood Network in Palliative Care are accepted models the world over. http://www.deccanchronicle.com/131012/news-current-affairs/article/big-strides-palliative-care

End-of-life care in Ireland

Design project grants dignity and grace to end-of-life care

IRELAND | *The Independent* (Dublin) – 29 September 2013 – How will you die? And where? When I was a child, I was taught to pray for a happy death. Implicit was the notion that it would be at home, surrounded by loved ones, having made peace with the world. But the reality is that although most of us would prefer to die at home, seven out of 10 of us will die in some form of care institution, and a fair percentage will die in an acute hospital. And even though we are living longer, and treatment options are expanding, those percentages will remain more or less as they are. Some years ago I attended the bedside of a friend who was dying in a Dublin hospital. She lived her last hours in a public ward with a television blaring out a football match, all but drowning our final conversation. I looked around this depressing place, with the cheap curtain separating her from other patients, walls painted nondescriptly institutional, the awful food, the ubiquitous smell of disinfectant mixed with human odour, and I began to think about the physical environment in which we might spend our final hours, that space which – as the late Seamus Heaney said – is "emptied" and "pure change" happens. http://www.independent.ie/lifestyle/design-project-grants-dignity-and-grace-to-endoflife-care-29618388.html

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Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

Selected articles on the architecturally design of hospices and palliative care facilities noted in past issues of Media Watch:

- SINGAPORE | *The Straits Times* – 24 September 2013 – **'Today's hospices are built for yesterday.'** Dying patients and their family members lack adequate private spaces as hospices are not designed to support palliative care services. Some hospices are also isolated from the community as there are no communal spaces or facilities the public can opt to use.[1] [Noted in Media Watch, 30 September 2013, #325 (p.6)] http://www.straitstimes.com/breaking-news/singapore/story/review-hospice-care-todays-hospices-are-built-yesterday-20130924

    1. 'Hospitable Hospice: Redesigning Care for Tomorrow,' Lien Foundation, ACM Foundation. https://www.dropbox.com/s/iwundjli0q6i854/HOSPITABLE%20HOSPICE%20I%20Ap.Issues%20&%20insights%20overview.pdf

- *HEALTHCARE DESIGN* | Online – 11 April 2013 – **'Making space for hospice in the care continuum.'** Designing for the continuum of care – architecturally and clinically – is all the rage... Some designers and care organizations feel that hospice and palliative care have been tucked in the back corner of eldercare... [Noted in Media Watch, 15 April 2013, #301 (p.5)] http://www.healthcaredesignmagazine.com/article/efa-2013-making-space-hospice-care-continuum

- *QJM* (Quarterly Journal of Medicine) | Online – 13 March 2013 – **'Patient dying in hospital: An honoured guest in an honoured place?'** In *Modern Hospice Design: The Architecture of Palliative Care* (London: Routledge, 2009) Ken Worpole reviewed the architecture and design of hospital spaces in which the dying find themselves. The idea of hospital being an honoured place with dying patients as honoured guests opens a new window into our daily reality of working in hospitals. [Noted in Media Watch, 25 March 2013, #298 (p.10)] http://qjmed.oxfordjournals.org/content/early/2013/03/13/qjmed.hct064.extract

- *DESIGN & HEALTH* | Online – 2 September 2010 – **'Palliative care unit design: Patient and family preferences.'** The primary purpose of this qualitative study was to identify what palliative care patients and their families perceive to be important elements in the design of a palliative care unit for end-of-life care. [Noted in Media Watch, 6 September 2010, #165 (p.8)] http://www.worldhealthdesign.com/Palliative-Care-Unit-Design.aspx

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (TASMANIA) | ABC News – 9 October 2013 – **'Academics, lawyers sound warning over euthanasia laws.'** Dr. Hannah Graham and Dr. Jeremy Prichard, from the University of Tasmania, have published a paper looking at the experience of jurisdictions where assisted suicide is legal.[1] They found evidence that safeguards were eroded over time, or ignored. Dr. Graham says vulnerable people are being euthanized without their explicit consent. Not enough is known about the risks and implications for vulnerable people in Tasmania, she said. But lawyers say the status quo is problematic. http://www.abc.net.au/news/2013-10-09/lawyers-sound-warning-over-euthanasia-laws/5011428?section=tas

    1. 'Voluntary Euthanasia and "Assisted Suicide" in Tasmania: A Response to [Premier Lara] Giddings & Greens Party Leader [Nick] McKim,' 8 October 2013. http://www.academia.edu/4703300/Voluntary_Euthanasia_and_Assisted_Dying_in_Tasmania_A_Response_to_Giddings_and_McKim_-_by_Hannah_Graham_and_Jeremy_Prichard

    Noted in Media Watch, 30 September 2013, #325 (p.7):

    - AUSTRALIA (TASMANIA) | ABC News – 26 September 2013 – **'Tasmanian MPS given conscience vote on euthanasia bill.'** MPs will be allowed a conscience vote on a private member's bill to introduce assisted dying laws being tabled in Parliament. The private member's bill is sponsored by the Premier, Lara Giddings and Greens Leader Nick McKim. http://www.abc.net.au/news/2013-09-26/tasmanian-mps-consider-euthanasia-bill/4981808

Cont.

- HUNGARY | Politics.hu – 9 October 2013 – **'Election committee rejects popular initiative on euthanasia.'** The new National Election Committee (OVB) unanimously rejected a popular initiative to permit active euthanasia. The committee, whose members were elected by Parliament late September, reversed the decision of its legal predecessor. The OVB's current decision essentially complies with a recent ruling of the Kuria [Supreme Court]. The question proposed for the popular initiative was as follows: "Do you agree that adults suffering from an incurable illness should be allowed to end their lives with medical assistance?" The Kuria annulled the previous decision, arguing that the question was misleading since it gave the impression the outcome of the initiative would determine the law. Passive euthanasia was authorised in Hungary under the 1997 Public Health Act. Fewer Hungarians support the principle of euthanasia now than a decade ago. http://www.politics.hu/20131009/election-committee-rejects-popular-initiative-on-euthanasia/

- SWITZERLAND | Expatica.com – 8 October 2013 – **'European rights court to rule on assisted suicide.'** The top chamber of the European rights court will rule in a case of denial of assisted suicide ... after a Swiss octogenarian complained she could not obtain permission for a lethal dose of a drug to commit suicide. In a lower chamber judgement in May the European Court of Human Rights held Swiss law does not clearly specify in which cases assisted suicide is authorised, causing ambiguity, and a "considerable degree of anguish" for the applicant. http://www.expatica.com/ch/news/swiss-news/european-rights-court-to-rule-on-assisted-suicide_275638.html

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

Similarities and differences in perspectives on interdisciplinary collaboration among hospice team members

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 October 2013 – This study surveyed four core hospice professionals (physicians, nurses, social workers, and chaplains) on their perceived level of interdisciplinary collaboration, the influences of interdisciplinary collaboration, and job satisfaction to determine potential similarities and differences based on profession and various demographic characteristics of the members or member hospices. Analysis found that there are overall no differences based on demographic characteristics. Differences between professions, while few, were largely in the area of perceptions on relationships between members of the hospice team. Specifically, social workers appear to perceive themselves as less connected to the other members of the interdisciplinary team [see sidebar, right], an area theorized to influence interdisciplinary collaboration. Difference between professions was also found in job satisfaction. http://ajh.sagepub.com/content/early/2013/10/10/1049909113503706.abstract

The lived experience of a critical illness – a social worker's reflection

ILLNESS, CRISIS & LOSS, 2013;21(3):231-245. Critical illness, admission to an intensive care unit, and prolonged hospitalization all impact on the psychosocial functioning of an individual. This article highlights my experience of a critical illness in an autoethnographic study thereby attempting to add knowledge to the scarcity of research from the patient's point of view. By writing this article, I was able to construct, deconstruct, and reconstruct my emotions, behavior, and the sequence of events in order to understand the impact of my critical illness. I ... invite healthcare professionals into my world of critical illness for better understanding of the patient's experience. http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,5,11;journal,1,75;linkingpublicationresults,1:103734,1

N.B. Several articles on the role of social workers in end-of-life care are noted in Media Watch, 10 June, 2013, #309 (pp.12-13).

Differences in end-of-life care in the ICU across patients cared for by medicine, surgery, neurology and neurosurgery physicians

CHEST | Online – 10 October 2013 – Some of the challenges in the delivery of high quality end-of-life care in the ICU include the variability in the characteristics of patients with certain illnesses and the practice of critical care by different specialties. [In this study] patients cared for by neurology and neurosurgery attending physicians have higher family and nurse ratings of quality of dying than patients cared for by medicine attendings and a different pattern of indicators of palliative care. Patients with surgery attendings had fewer documented indicators of palliative care. These findings may provide insights into potential ways to improve the quality of dying for all patients. http://journal.publications.chestnet.org/article.aspx?articleid=1750233

Noted in Media Watch, 7 October 2013, #326 (p.60:

- *BMC MEDICINE* | Online – 1 October 2013 – **'Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment & Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty.'** PACE provides individualized assessments of all patients entering the ICU. http://www.biomedcentral.com/content/pdf/1741-7015-11-213.pdf

Home care in the U.K.

Home care commissioning system "may be increasing risk of human rights abuses"

COMMUNITY CARE (U.K.) | Online – 8 October 2013 – Older people may be at increased risk of suffering human rights abuses as a result of local authority home care commissioning practices, according to a review by the Equality & Human Rights Commission (EHRC).[1] The report warns that the way home care is currently commissioned is unsustainable and leads to poor pay and working conditions for many care workers. This exacerbates the high turnover of staff, making care recipients more vulnerable to neglectful or abusive treatment. The EHRC says it recognises the severe financial pressures local authorities face, but adds that the rates some local authorities pay do not appear to cover the actual costs of delivering care. The report reviews 25 recommendations the EHRC originally made in its inquiry 'Close to Home.'[2] The inquiry found around half of older people were satisfied with their home care, but many others had experienced poor treatment or neglect. http://www.communitycare.co.uk/2013/10/08/home-care-commissioning-system-may-be-increasing-risk-of-human-rights-abuses/

Dying at home: A qualitative study of the perspectives of older South Asians living in the U.K.

PALLIATIVE MEDICINE | Online – 9 October 2013 – Two key themes were identified: "reconsidering the homeland" draws on the notion of "diaspora" to help understand why, for many study participants, the physical place of death was perceived as less important than the opportunity to carry out cultural and religious practices surrounding death; and, "home as a haven" describes participants' accounts of how their home is a place in which it is possible to perform various cultural and religious rituals. http://pmj.sagepub.com/content/early/2013/10/09/0269216313506765.abstract

1. 'Close to Home Recommendations Review,' EHRC, 2013. http://www.equalityhumanrights.com/uploaded_files/close_to_home_recommendations_review_web.pdf

2. 'Close to Home: An Inquiry into Older People and Human Rights in Home Care,' EHRC, 2011. http://www.equalityhumanrights.com/uploaded_files/homecareFI/home_care_report.pdf

Survey of controversial issues of end-of-life treatment decisions in Korea: Similarities and discrepancies between healthcare professionals and the general public

CRITICAL CARE | Online – 4 October 2013 – One thousand Koreans not working in healthcare and five hundred healthcare professionals responded [to the survey]. Over 50% thought that EOL treatment decisions should be made through discussions between the physician and the patient's family. For conflict resolution, 75% of Koreans not working in healthcare preferred direct settlement between the medical staff and the patient's family, while 55% of healthcare professionals preferred the hospital ethics committee. http://ccforum.com/content/pdf/cc13042.pdf

Of related interest:

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2013;15(7):410-418. **'Facilitators and barriers to use of advance directives in Korea.'** Seven barriers emerged [in this study]: negative attitudes, lack of a legal system, Korean Confucian belief, limited support, professional incompetence and advances in medical therapy. Public and professional education is believed to be critical... A legal model compatible with Korean culture is also needed. http://journals.lww.com/jhpn/Abstract/2013/10000/Facilitators_and_Barriers_to_Use_of_Advance.10.aspx

Noted in Media Watch, 10 June 2013, #309 (p.16):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2013;16(2):90-97. **'Public perception and acceptance of the National Strategy for Well-Dying.'** The most important factor was placing no burden of care on others (36.7%) and the second most important was staying with their family and loved ones (19.1%). Among nine suggestions of policy support for well-dying, the most popular was the promotion of voluntary care sharing (88.3%), followed by the palliative care training support for healthcare providers (83.7%) and the support for palliative care facilities instead of funeral halls (81.7%). The idea of formulating a five-year national plan for end-of-life care drew strong support (91%). According to the survey, the plan should be implemented by the central government (47.5%), the National Assembly (20.2%) or civic groups (10%). http://www.koreamed.org/SearchBasic.php?RID=0155KJHPC/2013.16.2.90&DT=1

Bridging the gaps in palliative care bereavement support: An international perspective

DEATH STUDIES, 2014;38(1):54-61. A review of palliative care policies and bereavement support practices in the U.S., Canada, U.K., Australia and Japan demonstrated four challenges: 1) questions over providing universal versus targeted support; 2) a lack of clear evidence driving service delivery; 3) informal or no risk assessment; and, 4) limited or no evaluation of services. Bridging the gaps between the policy and practice ... [and] ... support requires acknowledging the challenges of medical and public health models, improving bereavement need assessment processes, enhancing the role of primary care providers, and extending research to provide an evidence-base for interventions.http://www.tandfonline.com/doi/abs/10.1080/07481187.2012.725451

Of related interest:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 October 2013 – **'Parents' experiences of pediatric palliative care and the impact on long-term parental grief.'** Losing a child puts parents at increased risk for developing psychological problems. Both interaction with health care professionals, especially communication and continuity of care, and symptom management in children dying of cancer are associated with long-term parental grief levels. http://www.jpsmjournal.com/article/S0885-3924(13)00471-5/abstract

Quotable Quotes

Be patient enough to live one day at a time, letting yesterday go, and leaving tomorrow until it arrives. **Anon**

Medication appropriateness at end of life: A new tool for balancing medicine and communication for optimal outcomes – the BUILD model

HOME HEALTHCARE NURSE, 2013;31(9):518-524. The BUILD model was created to provide a systematic framework for hospice clinicians to have important conversations with patients and families as well as facilitating useful conversations with interdisciplinary teammates. Although this article focuses on medication appropriateness and discontinuation of medications, this model can also be used when discussing prognosis, code status, goals of care, drug diversion, and when collaborating to develop a plan of care. When provided with a communication tool that is versatile, logical, and effective, hospice clinicians may use it, supporting improved patient care outcomes. http://europepmc.org/abstract/MED/24081135

Of related interest:

- *PATIENT EDUCATION & COUNSELING* | Online – 5 October 2013 – **'Attitudes of nursing staff towards involvement in medical end-of-life decisions: A [Dutch] national survey study.'** Most respondents had been involved in ELD [end-of-life decisions]. Three quarters wanted to be involved in [the] whole ELD process; 58% agreed decisions to withhold/withdraw treatment ought to be discussed with the nurses involved; 64% believed patients would talk rather to nurses than physicians; 72% thought physicians are usually prepared to listen to nurses' opinions. http://www.sciencedirect.com/science/article/pii/S0738399113003935

Directive counsel and morally controversial medical decision-making: Findings from two national surveys of primary care physicians

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 10 October 2013 – Because of the potential to unduly influence patients' decisions, some ethicists counsel physicians to be nondirective when negotiating morally controversial medical decisions. Of 1,427 eligible physicians, 896 responded to Survey 1 (63 %). Physicians asked about morally controversial decisions were half as likely ... to endorse directive counsel. Of 986 eligible physicians, 600 responded to Survey 2 (61 %). Two in five physicians (41 %) endorsed directive counsel after reading a vignette describing a patient requesting palliative sedation to unconsciousness; these physicians tended to be male and more religioushttp://link.springer.com/article/10.1007/s11606-013-2653-4

Religious leaders' perspectives of ethical concerns at the end of life

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(7):396-402. The aims [of this study] were to describe the perspectives and experiences of religious leaders who have assisted individuals facing end-of-life ethical concerns and to evaluate the feasibility of conducting a larger study. Interviews were conducted ... with religious leaders from four different religions: Catholicism, Judaism, Islam, and Hinduism. Analysis revealed common themes among experiences of religious leaders, including respect and dignity of life and the body, challenges at end of life, and beliefs about the afterlife, which all have far-reaching effects on the practices at end of life. http://journals.lww.com/jhpn/Abstract/2013/10000/Religious_Leaders__Perspectives_of_Ethical.8.aspx

Of related interest:

- MEDSCAPE | Online (Commentary) – 1 October 2013 – **'Is it ethical to Tweet from someone's deathbed?'** If we are willing to get into this discussion, patients can make their wishes known before we get to the end of life. I think we need to ask patients to consent again, if possible, just to make sure that they are still fine with how their personal space and the most intimate of moments is being handled, whether or not it is good for the family or whether third parties agree. It is the individual's right to decide whether they want others to know about what is happening to them. http://www.medscape.com/viewarticle/811498_2

Emergency department utilization in the U.S.

Health care utilization by patients whose care is managed by a primary palliative care clinic

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2013;15(7):372-379. This study is consistent with evidence showing that palliative care patients often use health care resources, such as the emergency department [ED], for management of their needs. The findings also demonstrate that combined outpatient primary care and palliative care decrease ED utilization and hospital admissions in patients with life-limiting illness. Given the imminent changes to the U.S. health care system, including the establishment of accountable-care organizations charged with reducing ED utilization and hospital admissions, the dissemination of this study could have a significant impact on decreasing unnecessary health care utilization across the country. Further study is recommended to address the cultural needs and barriers of racial groups that demonstrate high utilization, to investigate how to better serve patients living with end-stage renal disease and non-cancer pain, and to further discern factors that may be impacting patients living in private homes. http://www.nursingcenter.com/lnc/CEArticle?an=00129191-201310000-00003&Journal_ID=260877&Issue_ID=1600457

Noted in Media Watch, 4 June 2012, #256 (p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE CARE* | Online – 23 May 2012 – **'Why do palliative care patients present to the emergency department? Avoidable or unavoidable?'** With an understanding of why patients present, interventions to avoid these presentations close to the end-of-life may be possible. A comprehensive, coordinated approach across community and acute services may help ensure patients are not sent to the ED inappropriately. http://ajh.sagepub.com/content/early/2012/05/18/1049909112447285.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 and research tool.

Distribution

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

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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.

Dignity in care: Time to take action

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 October 2013 – Patient care and caring about patients should go hand in hand. Caring implicates our fundamental attitude towards patients, and the ability to convey kindness, compassion and respect. Yet all too often, patients and families experience healthcare as impersonal, mechanical; and quickly discover that patienthood trumps personhood. The consequences of a medical system organized around care rather than caring are considerable. Despite technical competence, patients and families are dissatisfied with medical encounters when caring is less than evident. Lack of empathy and emotional disengagement often accompanies health care provider burnout. Caring is the gateway to disclosure; without it, patients are less likely to say what is bothering them, leading to missed diagnoses, medical errors and compromised patient safety. There are also liability issues, with most complaints levied against healthcare professionals stemming from failures in care tenor. Formal education for healthcare providers lacks a continued focus on achieving a culture of caring. If caring really matters, healthcare systems can insist on certain behaviors and impose certain obligations to improve care tenor, empathy, and effective communication. Caregivers need to be engaged in looking at their own attitudes towards patients, their own vulnerability, their own fears and whatever else it is that shapes their tone of care. Healthcare professionals must set aside some time, supported by their institutions, to advance a culture of caring – now is the time to take action. http://www.jpsmjournal.com/article/S0885-3924(13)00452-1/abstract

Of related interest:

- *JOURNAL OF THE ROYAL SOCIETY OF MEDICINE* | Online – 9 October 2013 – **'Compassion in healthcare – lessons from a qualitative study of the end-of-life care of people with dementia.'** The concepts of compassion, kindness and humanity in dementia care are discussed within this paper. The ability to deliver care that is compassionate, kind and humanistic exists along a continuum across care settings – examples of excellent care sit alongside examples of very poor care and the reasons for this are explored together with discussion as to how health and social care staff can be trained and supported to deliver compassionate care. http://jrs.sagepub.com/content/early/2013/09/16/0141076813503593.abstract

Current state of psychiatric involvement on palliative care consult services: Results of a [U.S.] national survey

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 4 October 2013 – The survey had a 59% response rate, with final analyses including surveys completed by 260 palliative care program directors. Seventy-two percent of respondents reported some form of involvement with a psychiatrist on their palliative care service, with only 10% of those identifying a psychiatrist as a full- or part-time member of the team. Most respondents reported that they would like psychiatrists to be more involved with the palliative care services (71%). Secondary analyses of qualitative responses identified common impediments to increased psychiatry involvement, which included financial constraints, provider interest, and perceived disciplinary disconnect. There are shared objectives between psychiatry and palliative care; however, currently, co-involvement on treatment teams is quite limited. Future research is needed to identify ways to facilitate the interface of palliative care and psychiatry. http://www.jpsmjournal.com/article/S0885-3924(13)00401-6/abstract

Noted in Media Watch, 1 July 2013, #312 (p.8):

- *CURRENT PSYCHIATRY REPORTS* | Online – 22 June 2013 – **'Palliative care psychiatry: Update on an emerging dimension of psychiatric practice.'** The discipline brings expertise in understanding the psychosocial dimensions of human experience to the care of dying patients and support of their families. http://link.springer.com/article/10.1007/s11920-013-0374-3

End-of-life care in France

Soins palliatifs en établissement d'hébergement pour personnes âgées dépendantes: État des lieux, problématiques et perspectives

(Palliative care in nursing homes: Current status, problems and prospects)

MÉDECINE PALLIATIVE | Online – 11 October 2013 – Nursing homes are actors in France in support of the end of life. As part of the 2008-2012 development program of palliative care, several concrete measures or devices have been introduced to assist nursing home professionals to implement palliative care in institutions. At the completion of this program, an initial assessment revealed significant problems. The analysis of these issues allowed considering possible improvements. In fact, three very specific phenomena emerged: the lack of the presence of a night nurse, the finding of a subpopulation of elderly requiring both institutionalization in nursing homes and more consistent technical care and the difficulty to develop an individualized plan of care. http://www.sciencedirect.com/science/article/pii/S1636652213001062

Narratives of aggressive care: Knowledge, time, and responsibility

NURSING ETHICS | Online – 7 October 2013 – While witnessing and providing aggressive care have been identified as predominant sources of moral distress, little is known about what nurses "know" to be the "right thing to do" in these situations. The purpose of this study was to explore what nurses' moral knowledge is in situations of perceived overly aggressive medical care. Four narrative types were identified: "Wait and see: medical uncertainty," "Deflected responsibilities to respond to dying, death, or futility," "Divergent understandings, responsibilities, and temporalities," and "Privileged medical understandings and responsibilities." The knowledge of differentially situated persons is acknowledged in dissimilar ways, the time required to determine that enough has been done is perceived differently, and how moral responsibilities are understood also varies. http://nej.sagepub.com/content/early/2013/10/03/0969733013502804.abstract

Analysis of current conditions concerning development of palliative care in three selected countries of the former Eastern Bloc

POLSKI MERKURIUSZ LEKARSKI (Organ Polskiego Towarzystwa Lekarskiego – Polish Medical Association), 2013;35(206):89-93.The term "palliative care" is not commonly known in either of the countries analyzed [Belarus, Kazakhstan, Ukraine]. Full-time hospices or palliative care units function in all of three, and palliative care services are publicly funded, however, only in part. Patients do not have access to opioids in amounts required for regular daily use. No differences as to the barriers [to] palliative care development between the analyzed countries were identified. http://europepmc.org/abstract/MED/24052988/reload=0;jsessionid=ynMLR5Y7Ln7H7sgUIJ49.38

Noted in Media Watch, 20 May 2013, #306 (p.6):

- UKRAINE | Reuters – 15 May 2013 – **'New breakthrough for incurably ill.'** Ukraine's cabinet of ministers' approval of new regulations on access to pain medicines will dramatically expand healthcare services for patients with incurable illnesses and reduce unnecessary suffering. A Human Rights Watch report in 2011 concluded that tens of thousands of cancer patients in Ukraine die every year in severe pain because they cannot get adequate palliative care services.[1] http://www.trust.org/item/20130515040000.0000-g96tq/

    1. *Uncontrolled Pain: Ukraine's Obligation to Ensure Evidence-Based Palliative Care*, Human Rights Watch, 12 May 2011. [Noted in Media Watch, 16 May 2011, #201 (p.4)] http://www.hrw.org/en/reports/2011/05/12/uncontrolled-pain-0

Cont.

Of related interest:

- *JOURNAL OF CANCER EDUCATION* | Online – Accessed 8 October 2013 – **'Attitudes of Polish physicians and medical students toward breaking bad news, euthanasia and morphine administration in cancer patients.'** 82% of students and 90% of physicians [i.e., survey participants] would not practice euthanasia; 67% of students and 75% of physicians were opponents of euthanasia legalisation; 70% doctors and 23% students indicated oral as the most preferable route of morphine administration; and, 74% physicians and 43% students stated that there is no maximal dose of morphine; Breaking bad news is a significant difficulty for both students and physicians. http://link.springer.com/article/10.1007/s13187-013-0553-2/fulltext.html#Sec8

Media Watch Online

International

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

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

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

PALLIMED (Hospice & Palliative Medicine Blog): http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html (Scroll down to 'Aggregators' and Barry Ashpole and Media Watch)

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: HTTP://APHN.ORG/CATEGORY/MEDIA-WATCH/

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

Australia

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

Canada

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

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

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

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

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

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

Europe

HUNGARY | Hungarian Hospice Foundation: http://www.hospicehaz.hu/en/training/ (Scroll down to 'Media Watch')

U.K. | Omega, the National Association for End of Life Care: http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c

Palliative care for frail older people: A cross-sectional survey of patients at two hospitals in England

PROGRESS IN PALLIATIVE CARE, 2013;21(5):272-277. The majority of deaths in the U.K. occur in acute hospitals, and older people have the highest hospital death ... yet little is known about the profile of older patients with palliative care needs in hospitals. While this study is limited by its small sample size, the results suggest that older people with frailty conditions constitute a substantial proportion of hospital inpatients with palliative care needs. However, it is unclear whether a specialist palliative care framework is the most appropriate model for this group. The care provided to older people at the end of life may best be provided by generalists such as geriatricians, as part of a comprehensive generalist-led palliative care framework. http://www.ingentaconnect.com/content/maney/ppc/2013/00000021/00000005/art00003

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *GENERAL HOSPITAL PSYCHIATRY* | Online – 3 October 2013 – **'Psychiatric review should be mandatory for patients requesting assisted suicide.'** No jurisdiction currently holds a policy of mandatory psychiatric review for all applicants requesting assisted suicide. http://www.ghpjournal.com/article/S0163-8343(13)00240-5/fulltext

Worth Repeating

Where do nurses go for help? A qualitative study of coping with death and dying

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2013;16(9):432-438. As end-of-life care becomes a more prominent issue in health care, it is important to address the experience from the caregivers' perspective. In order to cope with the stressful experience of caring for a dying patient, nurses need programmes that both help them develop coping strategies and prepare them for caring for dying patients as well as resources to help them cope with the experience once it has happened. Because little is known about the coping habits of nurses facing the death of a patient, research is needed that examines their coping responses to develop more effective resources. This research examines the resources that nurses use when coping with the death of a patient. The results of this research indicate that communication with patients and their families, as well as coworkers, is an integral part of that process. http://www.internurse.com/cgi-bin/go.pl/library/abstract.html?uid=78636

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