Media Watch...

is intended as an advocacy, research and teaching 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 2008-2015 ©

Compiled & Annotated by Barry R. Ashpole

Evaluating the impact of hospice / palliative care services: Scroll down to <u>Specialist Publications</u> and 'The population burden of chronic symptoms that substantially predate the diagnosis of a life-limiting illness' (p.12), in *Journal of Palliative Medicine*.

Canada

Health care system to feel strain of aging population: Report

BRITISH COLUMBIA | News 1130 (Vancouver) – 15 April 2015 – If something isn't done now, our health care system will be in big trouble 25 years from now, that's the finding of a report from the Conference Board of Canada.¹ It says the number of seniors in the country is expected to double between now and then, from 5 million to 10 million, and Dr. Gabriela Prada, who is one of the study's authors, says most of us are unaware of the consequences. As the number of seniors increases, so will the demand for hospital services, home care, and long-term care and the current system is already struggling. "The health care costs per capita tend to increase every year of life after 65, so it's not only the volume of seniors but also the seniors aging within that population that is going to have a very important impact on health care costs. At the same time, there are some other consequences of aging, so there will be a reduction in Canada's labour pool because there will be less people working and that will impact our health human resources and likely will aggravate some of the shortages that exist today within health care services." "There will also be a decline in the tax base that funds health services. By 2030, the number of working age Canadians for every senior will drop to 2.7 from 5 in 2010 ... and that will have significant repercussions, because we won't be able to raise the same amount of money to cover healthcare services." Governments are not prepared ... adding although strategies are being discussed, there's nothing really in place. http://www.news1130.com/2015/04/15/healt h-care-system-to-feel-strain-of-agingpopulation-report/

Conference Board of Canada observations on end-of-life care

Noting that delivery of these services can vary widely across jurisdictions and is often uncoordinated, the authors single out concerns about palliative care. "Few of those seniors who require palliative care actually receive it ... and those who do often experience a patchwork of uncoordinated services."

1. 'Understanding Health and Social Services for Seniors in Canada,' Conference Board of Canada, April 2015. <u>http://www.conferenceboard.ca/e-library/abstract.aspx?did=7025</u>

Of related interest:

- ONTARIO | *The Toronto Star* 14 April 2015 'Older patients face gaps in health care: Report.' Older patients often fall through the cracks when they move between doctors, hospitals and other parts of parts of Ontario's health system, a new report says.¹ Too often, their records don't follow them, they don't get important questions answered between appointments, and they don't get written instructions for self care after leaving hospital... http://www.thestar.com/life/health wellness/2015/04/14/older-patients-face-gaps-in-health-care-report.html
 - 'Experiencing Integrated Care: Ontarians' views of health care coordination and communication,' Health Quality Ontario, April 2015. The report is based on the 2014 'Commonwealth Fund International Health Policy Survey of Older Adults' [Noted in Media Watch, 9 February 2015, #396 (p.3)] and compares Ontario's performance with the other provinces in Canada and ten other countries <u>http://www.hqontario.ca/Portals/0/documents/pr/report-experiencingintegrated-care-1504-en.pdf</u>

N.B. There is no mention in this report of hospice or palliative care or of the needs of people living with life-threatening or life-limiting illnesses.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

CANADIAN FAMILY PHYSICIAN, 2015;61(4):e196e203. 'Health care professionals' comprehension of the legal status of end-of-life practices in Quebec: Study of clinical scenarios.' This study revealed misunderstandings about which end-of-life practices were currently legal in Quebec. Some respondents believed using opioids adjusted to symptom relief was not permitted. Furthermore, nearly half of respondents believed treatment withdrawal upon the patient's request had yet to be legalized. Misunderstandings surrounding the current legal status of medical practices were more common among those who obtained their diplomas longer ago and among nurses. Nonetheless, nearly 1 in 3 family physicians and 2 in 5 other specialists demonstrated the same misunderstanding, underscoring the importance of continuing medical education regarding end-of-life care. No difference in comprehension was observed between those who cared for dying patients in their clinical practices and those who did not; this deserves special consideration in future studies. More than 60% of respondents believed the use of lethal medication upon the patient's request would remain illegal if medical aid in dying were authorized in Quebec. Also, 34.6% of professionals believe that the use of lethal medication would be legal when requested by a relative, despite the fact that a voluntary request by a competent patient has been proposed as a necessary condition by Quebec government reports since 2012. all http://www.cfp.ca/content/61/4/e196.full.pdf+html

Sp<u>ecialist</u> Publications

'Is physician-assisted death in anyone's best interest? Yes' and 'Is physician assisted death in anyone's best interest? No' (pp.14-15), in *Canadian Family Phy*sician.

Specialist Publications

'Taking action: An exploration of the actions of exemplary oncology nurses when there is a sense of hopelessness and futility perceived by registered nurses at diagnosis, during treatment, and in palliative situations' (p.10), in *Canadian Nursing Oncology Journal.*

'Paediatric palliative care in Canada: A national survey of paediatricians' (p.13), in Paediatrics & Child Health.

Lawmakers debate whether pregnant women should get to make their own end-of-life decisions

TEXAS | *The Observer* (Austin) – 16 April 2015 – The House State Affairs Committee heard a bill Wednesday that would allow pregnant women and their families to make their own end-of-life decisions. Currently, under Texas' advance directive law, doctors "may not withdraw or withhold life-sustaining treatment ... from a pregnant patient," a little-known clause that drew national attention when a pregnant woman in Fort Worth was declared brain dead in 2013. https://www.texasobserver.org/lawmakers-debate-whether-pregnant-women-should-get-to-make-their-own-end-of-life-decisions/

End-of-life care needs an overhaul

MASSACHUSETTS | The Boston Globe (Commentary) - 15 April 2015 - For three decades, hospitals and doctors have been encouraging patients to complete advance directives - legal documents that either specify what actions should be taken if patients are no longer able to make decisions for themselves or designate a person to make decisions on their behalf when they are incapacitated. Health care systems continue to pour millions of dollars into urging patients to complete these paper forms. Unfortunately ... they usually don't work. In my 15 years of medical practice, these documents rarely - if ever - preserved the patient's voice when it was most needed. I care for seriously ill patients in a hospital setting when they are most sick and often unable to speak for themselves. I also have usually never met the patient prior to meeting them in the hospital. In the rare event that the patient has actually completed an advance directive describing their wishes and I have access to these forms, the legalistic language makes them difficult to integrate into clinical care and often don't help clarify patients' values. Worse vet are forms in which patients designate a person ... to speak on their behalf when they are no longer able to. Most of the time, patients have named someone with whom they have not discussed their health care wishes. I often find myself talking about decisions with a son or daughter who never had a conversation with their parents about what they wanted. http://www.bostonglobe.com/opinion/2015/0 4/15/end-life-care-needsover-

haul/Gr2w1lesb5dj1ddnbmipBJ/story.html

Extract from *The Boston Globe* commentary

The daunting statistics related to end-of-life care have been well-publicized: Most Americans die in hospitals even though most would prefer to die at home, and one out of three Medicare dollars is spent in the last few months of people's lives.

Specialist Publications

'Dying in the age of choice' (p.13), in *Journal of Social Work in End-Of-Life & Palliative Care.*

Palliative Care Bill signed into law

OKLAHOMA | *The Edmond Sun* – 14 April 2015 – An advisory panel that helps to set state health policies would have more input from experts on the coordinated care of patients with chronic conditions under a measure signed into law yesterday. House Bill 1085 ... renames the Home Care & Hospice Advisory Council to the Home Care, Hospice & Palliative Care Advisory Council and adds two members who specialize in palliative care. The measure directs the council to identify ways to improve the quality and delivery of palliative care. The American Cancer Society and Oklahoma State Department of Health were both strong supporters of the legislation. http://www.edmondsun.com/news/state news/palliative-care-bill-signed-into-law/article 4820af18-e2e8-11e4-9305-bf2de9b1e919.html

Elder care costs keep climbing; nursing home bill now \$91K

ASSOCIATED PRESS | Online - 12 April 2015 - The steep cost of caring for the elderly continues to climb. The median bill for a private room in a nursing home is now \$91,250 a year... The annual 'Cost of Care' report from Genworth Financial tracks the rise in expenses for long-term care, a growing financial burden for families...¹ The cost of staying in a nursing home has increased 4% every year over the last five years... Last year, the median bill was \$87,600. One year in a nursing home now costs nearly as much as three years of tuition at a private college. For its report, Genworth surveyed 15,000 nursing homes, assisted living facilities and other providers across the country in January and February. It found wide differences from state to state. In Oklahoma, for instance, the median cost for a year in a nursing home came out to \$60,225. In Connecticut, it was \$158,775. Alaska had the highest costs by far, with one year at \$281,415. http://krqe.com/2015/04/12/elder-care-costskeep-climbing-nursing-home-bill-now-91k/

Specialist Publications

'Why it's not time for health care rationing' (p.10), in *The Hastings Report*.

1. 'Compare Long Term Care Costs Across the U.S.,' Genworth Financial, April 2015. https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html

Consequences of shifting demographics

Hospice volunteers provide end-of-life companionship as more age at home

CALIFORNIA | The Sacramento Bee - 11 April 2015 – Over the past decade, the hospice industry has seen substantial growth with the aging baby boomer population. Adults over 50 are expected to make up 20% of the population by 2030, and 90% of Americans want to grow older at home... Demand for elder care, including end-of-life care, is up across the board. Personal and home health aides ... are the second- and third-fastest-growing occupations in the U.S., as ranked by the Bureau of Labor Statistics. The Sacramento Hospice Consortium, a network of not-for-profit, Medicarecertified hospice providers in the Sacramento area, is feeling the shift in demographics. In one program, the number of patients has more than doubled from 60 to 140 over the past year... About 10% of the

1,000 patients the consortium serves at a given time are over 100 years old, and many have primary caregivers in their 70s and 80s who depend on hospice volunteers for help. http://www.sacbee.com/news/local/health-and-medicine/healthy-choices/article18300686.html

Extract from The Sacramento Bee article

Hospice is also increasingly seen as a money saver, compared to nursing homes and other facilities. The National Aging in Place Council estimates that care can cost on average \$86,000 annually per person in a nursing home, \$60,000 for someone in assisted living and \$23,000 for someone aging at home.



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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HARTFORD BUSINESS JOURNAL | Online 17 April 2015 'Connecticut not alone in stalled assisted-suicide legislation.' Connecticut lawmakers aren't the only ones uncomfortable with legalizing assisted suicide, according to a poll commissioned by the Catholic fraternal organization Knight of Columbus.¹ Similar bills have stalled this year in state legislatures in Maryland, Colorado and Nevada. The poll found 43% of Americans support a doctor prescribing or administering a lethal drug dose, 36% oppose it, and 21% don't have a position. http://www.hartfordbusiness.com/article/20150417/NEWS01/150419946
 - Would Connecticut residents trust a doctor who believes he or she should participate in end of life decisions? Adults state-wide divide,' Knight of Columbus/ Marist Poll, March 2015. <u>http://www.kofc.org/un/en/resources/communications/ct-residents-not-in-favor-doctorsadministering-prescribing-fatal-drugs.pdf</u>

International

End-of-life care in Australia

Palliative care services in Victoria overwhelmed: Auditor-General report finds

AUSTRALIA (Victoria) | The Sydney Morning Herald - 15 April 2015 - Dying people in Victoria are facing waiting lists of up to six weeks for specialist care to relieve their pain and suffering and many who want to die at home are not able to because palliative care services are overwhelmed, an audit has revealed.¹ An Auditor-General investigation found that in 2012-2013, 67% of people who died in the care of a Victorian community palliative care service recorded their preferred place of death. While most indicated they would prefer to die at home - a much cheaper option than hospital care - only half were able to do so. The report ... said some people in inner metropolitan areas had faced "extended" waits for support at home in the past and that this was likely to happen again as demand continues to increase. "This remains a major concern for metropolitan inpatient facilities wishing to discharge patients to the community. It could potentially result in patients staying in hospital longer than they want, or receiving basic, non-palliative care in the home, or even re-presenting to hospital if symptoms escalate or become distressing," the report said. While the investigation reported that Victoria had a strong palliative care sector, with dedicated and skilled staff, a departmental review in 2014 found that most palliative care services did

not meet expected standards. Some believed they were better than they really were. <u>http://www.smh.com.au/national/health/pallia</u> <u>tive-care-services-in-victoria-overwhelmed-</u> <u>auditorgeneral-report-finds-20150415-</u> <u>1mltei.html</u>

Extract from the Auditor General's report

About 36 000 people die in Victoria each year and this figure is projected to double in the next 25 years. Of those people, about half will die following a period of chronic illness such as heart disease, cancer, stroke or neurological illness – it is these people who will most benefit from palliative care.

Specialist Publications

'Practices of end-of-life decisions in 66 southern French ICUs 4 years after an official legal framework: A 1-day audit' (p.14), in *Anaesthesia Critical Care & Pain Medicine*.

'European palliative care guidelines: How well do they meet the needs of people with impaired cognition?' (p.9), in *BMJ Supportive & Palliative Care* 'Palliative Care,' Victorian Auditor-General's Office, 15 April 2015. The audit examined policies and procedures of the Department of Health & Human Services and four health services. http://www.audit.vic.gov.au/publications/20150415-Palliative-care/20150415-Palliative-care.pdf

Noted in Media Watch, 26 January 2015, #394 (p.12):

MEDICAL JOURNAL OF AUSTRALIA, 2015;202(1):10-11. 'What can we do to help Australians die the way they want to?' Australians are not dying as they would wish. Surveys consistently show that between 60% and 70% of Australians would prefer to die at home, and that residential care facilities are their least preferred option. Dignity, control and privacy are important for a good death. Choice over who will be present, where people will die and what services they will get, matters. <u>https://www.mja.com.au/journal/2015/202/1/what-can-we-dohelp-australians-die-way-they-want</u>

Elder care in the U.K.

Humanity lies at the heart of a National Health Service worth keeping

U.K. | The Guardian (Commentary) - 13 April 2015 - The GP who gives his home phone number to palliative care patients' families at weekends in case they need him. The nurse who brought her patient's sister to A&E [Accident & Emergency] after a busy afternoon outpatient clinic, because they needed support to get there. The lung transplant physician who remembers the intricate. non-medical details of his patients' lives because, in his own words, he has "journeyed with them for years." The junior doctor who made time in his night shift break to catch up with the man on a different ward who survived a stroke the previous night. The anaesthetist who interrupted a twin caesarean section to make sure the surgeon told the parents which baby was which, so they could name them the way they had planned to. The oncologist who continued her clinic after news of a family bereavement because her patients had already been kept waiting to see her. People caring for people. Humanity touching humanity. The technology, knowledge and skills within the NHS [National Health Service] are vast. But these things alone are not what give me hope for it. They are not what will persuade me to be a doctor. What encourages me are the moments of hope and care and wholeness. Holistic care, from individuals, to individuals. This is what inspires me. This is the NHS. http://www.theguardian.com/healthcarenetwork/views-from-the-nhs-

frontline/2015/apr/13/humanity-lies-at-heartnhs Elder care in England

A million elderly people lack basic social care as unprecedented funding cuts leave struggling National Health Service to pick up the pieces

U.K. (England) | The Independent – 12 April 2015 - The leading charity Age UK estimated last year that 900,000 people in England between the age of 65 and 89 have unmet social care needs, but experts at the charity now believe the figure is closer to one million. Caroline Abrahams, Age UK's chief executive, said that the issue of social care was the single most important issue for elderly voters going into next month's election. But she warned it was not being talked about enough and had been put in "the too-difficult box" by politicians. The reason for that, Ms. Abrahams said, was, in part, because most of the current crop of top politicians may be "too young" to have seen the impact of social care cuts on their own parents. 40% cuts to government funding for local councils, which provide the bulk of social care, have had a devastating impact on elderly people. http://www.independent.co.uk/life-style/healthand-families/health-news/a-million-elderly-peoplelack-basic-social-care-as-unprecedented-fundingcuts-leave-struggling-nhs-to-pick-up-the-pieces-10170302.html

Of related interest:

- U.K. | BBC News 17 April 2015 'Warning of 'funeral time bomb' in U.K. as population ages.' The U.K. death rate has reached a tipping point with numbers of deaths expected soon to begin rising after falling for decades, suggests a report.¹ The oldest of the post war babyboom generation, born in 1945, will turn 70 this year... The number of deaths is likely to rise 20% over the next 20 years... http://www.bbc.com/news/education-32349490
 - 1. 'The funeral time bomb,' International Longevity Centre, April 2015. http://www.ilcuk.org.uk/index.php/news/news_posts/press_release_till_debt_do_us_part
- NATIONAL COUNCIL FOR PALLIATIVE CARE | Online 17 April 2015 'Political party manifesto commitments on end-of-life care.' With the general election under three weeks away, the five political parties have all made reference to end of life care in their manifestos. <u>http://www.ncpc.org.uk/sites/default/files/2015%20Manifesto%20Commitments%20on%20En</u> d%20of%20Life%20Care.pdf

Pushing for end-of-life care in Malaysia

MALAYSIA / *The Star* (Kuala Lumpur) – 12 April 2015 – The practice of palliative or end-of-life care for patients with life-threatening illnesses is still at its infancy in Malaysia. But the Government is pushing for greater interest by medical practitioners and support personnel in this important area. As the country's standard of living improves, there is also an increase in awareness of the need to ensure good quality of life, despite having illnesses, and the provision of end-of-life care in conditions where cure is not possible. Previously, palliative care was only provided to patients with late-stage cancer. Today, however, palliative care is being provided to patients with non-cancerous life-limiting conditions, says Dr Richard Lim Boon Leong, a pioneer in palliative care in Malaysia. http://www.thestar.com.my/Lifestyle/Health/2015/04/12/Pushing-for-endoflife-care-in-Malaysia/

N.B. Malaya was rated 33rd (of 40 countries surveyed) in *The Quality of Death: Ranking End of-life-Care Across the World*, commissioned by the Lien Foundation, Singapore, and published by the Economist Intelligence Unit, 2010. [Noted in Media Watch, 19 July 2010, #158 (p.3)] Scroll down to <u>Worth Repeating</u> (p.16), and '2010 ranking of end-of-life care across the world.'

Elder care in Singapore

Manpower biggest issue in meeting new nursing home standards

SINGAPORE | Channel NewsAsia – 12 April 2015 – Nursing homes ... say lack of manpower is the biggest issue they face following the introduction of the new enhanced nursing home standards this month. The Government implemented the standards in April 2015 to ensure that seniors receive consistent quality care. Over 90% of nursing homes have participated in a voluntary baseline assessment by the Agency for Integrated Care to identify potential areas for improvements to meet the new standards. The new standards are divided into ... clinical areas such as pain management and advanced care planning, social aspects like dignity of care and psychosocial well-being, and the area of governance such as staff training and emergency preparedness. http://www.channelnewsasia.com/news/singapore/manpower-biggest-issue-in/1779938.html

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.15.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

IRELAND | *The Journal* (Dublin) – 13 April 2015 – '**The facts about assisted suicide in Ire**land.' Gail O'Rouke is the first person in Ireland to ever be charged with assisting suicide. Her trial was due to start today but has been adjourned to a later date. This will be a trial that will be watched intently by many. Because no one has ever been charged with this offence before, there is little precedence for this kind of case. However, the law does make it clear that assisting another person to end their own life is a criminal offence. Both euthanasia and assisted suicide are included in this. It is not against the law to switch off life support or stop certain treatments (like chemotherapy) if a person or their next of kin requests it. However guidelines for doctors are clear: they "must not participate in the deliberate killing of a patient by active means." <u>http://www.thejournal.ie/explainer-assisted-suicide-2045083-Apr2015/</u>

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

Is death our business? Philosophical conflicts over the end-of-life in old age psychiatry

AGING & MENTAL HEALTH | Online – 14 April 2015 – Old age psychiatrists work with end-of-life (EOL) issues and encounter patient deaths, but death and dying have received limited focus in old age psychiatry training and research. Two dichotomous overarching themes were identified. Death is not our business reflected [study] participants' experience of working in a mental health framework and incorporated four themes: 1) death should not occur in psychiatry; 2) working in a psychiatric treatment model; 3) keeping a distance from death; and, 4) unexpected death is a negative experience. Death is our business reflected participants' experience of working in an aged care context and incorporated four themes: 1) death is part of life; 2) encountering the EOL through dementia care; 3) doing EOL work; and, 4) expected death is a positive experience. Participants reported conflict because of the contradictory domains in which they work. http://www.tandfonline.com/doi/abs/10.1080/13607863.2015.1031636#.VS5fXWdFCos

Noted in Media Watch, 1 December 2014, #386 (p.12):

- PSYCHIATRY TIMES | Online 25 November 2014 'Psychiatry's place in caring for the terminally ill.' The Institute of Medicine recently released its report [on end-of-life care in the U.S.] and its general thrust is that we have a long way to go in providing appropriate care for those nearing the end of their lives.¹ There are several portions of special importance to psychiatrists, especially the discussion of the role psychiatrists could and ... should be playing... http://www.psychiatrictimes.com/cultural-psychiatry/psychiatrys-place-caring-terminally-ill
 - 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <u>http://www.iom.edu/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf</u>

Patient safety and end-of-life care: Common issues, perspectives, and strategies for improving care

AMERICAN JOURNAL OF HOSP[ICE & PALLIATIVE MEDICINE | Online – 15 April 2015 – This article synthesizes recent systematic reviews and additional research on improving patient safety and end-of-life care and compares each field's perspective on common issues, both in traditional patient safety frameworks and in other areas, and how current approaches in each field can inform the other. The article then applies these overlapping concepts to a key example area: improving documentation of patient preferences for life-sustaining treatment. The synthesis demonstrates how end-of-life issues should be incorporated into patient safety initiatives. http://ajh.sagepub.com/content/early/2015/04/15/1049909115581847.abstract

European palliative care guidelines: How well do they meet the needs of people with impaired cognition?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 April 2015 – Eleven countries identified palliative care guidelines, 10 of which mentioned pain management in general. Of these, seven mentioned cognitive impairment... Half of guidelines recommended the use of pain tools for people with cognitive impairment; recommended tools were not all validated for the target populations. Guidelines from the U.K., The Netherlands and Finland included most information on pain management and detection in impaired cognition. Guidelines from Iceland, Norway and Spain scored most highly on Appraisal of Guidelines Research & Evaluation instrument rating in terms of developmental quality. European national palliative care guidelines may not meet the needs of the growing population of people dying with cognitive impairment. New guidelines should consider suggesting the use of observational pain tools for people with cognitive impairment. Better recognition of their needs in palliative care guidelines may drive improvements in care. http://spcare.bmj.com/content/early/2015/04/13/bmjspcare-2014-000813.abstract

Of related interest:

DEMENTIA | Online – 16 April 2015 – 'General practitioners' perceptions of the barriers and solutions to good-quality palliative care in dementia.' Barriers ... were perceived to be a knowledge deficit for healthcare staff and the public, a resource shortfall within the GP practice and community, poor team coordination alongside inappropriate dementia care provision, and disagreements from and within families. These findings have significant implications for educators and clinicians as enhanced dementia education and training were highlighted as a strong agenda for GPs with the suggestions of dementia awareness programmes for the public. http://dem.sagepub.com/content/early/2015/04/16/1471301215581227.abstract

Structured touch

Applying the M technique in palliative and end-of-life care

BRITISH JOURNAL OF HEALTHCARE ASSISTANTS | Online – 10 April 2015 – Many of us are afraid to use touch for those who need it most. It can be a powerful and comforting way of communicating, particularly for those who require palliative and end-of-life care. This article demonstrates how healthcare assistants ... used the M technique to encourage staff and carers to use touch in a meaningful way ... to involve those close and special to the patient by giving them permission to touch. http://www.magonlinelibrary.com/doi/abs/10.12968/bjha.2015.9.4.180



Taking action: An exploration of the actions of exemplary oncology nurses when there is a sense of hopelessness and futility perceived by registered nurses at diagnosis, during treatment, and in palliative situations

CANADIAN NURSING ONCOLOGY JOURNAL, 2015;25(2):179-185. "There is nothing more that can be done" is a phrase that may occasionally cross the minds of oncology nurses. This paper reports on the actions of exemplary oncology nurses who were faced with such situations where colleagues gave up or turned away. The question, "What actions do exemplary clinical oncology nurses undertake in patient-care situations where further nursing interventions seem futile?" prefaced data collection via a secure website where 14 Canadian clinical oncology registered nurses provided narratives documenting their actions. Four themes were generated: 1) advocacy; 2) not giving up; 3) genuine presence; and, 4) moral courage. Implications for practice and research are provided. http://www.canadianoncologynursingjournal.com/index.php/conj/article/view/309

Why it's not time for health care rationing

THE HASTINGS REPORT, 2015;45(2):15-19. Discussion of health care rationing, which was hotly debated in the nineties, has become much more muted. Is health care rationing *passé*? I contend that debates about health care rationing have waned not because the need to ration has dwindled nor because ethical debates about how or whether to ration have been resolved. They have declined because the word "rationing," and unrelated concepts such as cost-effectiveness analysis, have been replaced by terms – "parsimony," "value," and "CER" [comparative effectiveness research] – that are not burdened by emotional and historical baggage. Sometimes the best way to promote healthy moral debate is to turn to new words that don't carry the burden of past debates. http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=7305

Awareness of palliative care among doctors of various departments in all four teaching medical colleges in a metropolitan city in Eastern India: A survey

JOURNAL OF EDUCATION & HEALTH PROMOTION | Online – 26 March 2015 – 85% of the doctors [surveyed] felt that cancer was the commonest reason for the palliative care teams to be involved. 74%... mentioned that pain control was their prime job; 53% said that they are enjoying their encounter with palliative care, so far; 77% of the doctors thought that breaking bad news is necessary in further decision making process; only 22% of the doctors reported the WHO ladder of pain control sequentially, 35% of the doctors believed other forms of therapies are useful in relieving pain, 35% of the doctors thought they gave enough importance and time for pain control; 77% said they had heard about a hospice, among them still 61% of the doctors thought the patients should spend last days of their life at home. http://www.jehp.net/article.asp?issn=2277-9531;year=2015;volume=4;issue=1;spage=20;epage=20;aulast=Bhadra

Correlates and predictors of conflict at the end of life among families enrolled in hospice

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 April 2015 – Although overall levels of conflict were relatively low [in this study], 57% of hospice caregivers reported experiencing some family conflict at the end of life. Contextual variables associated with family conflict included a history of family conflict, female gender, younger caregiver age, presence of children in the home, and less advance care planning discussions. Significant main effects in the prediction of family conflict in the final hierarchical multiple regression model included prior family conflict, caregiver age, caregiver gender, advance care planning discussions, family "coming out of the woodwork," communication constraints, and family members asserting control. The model explained 59% of the variance in family conflict. Results support the multidimensional theoretical model of family conflict specifying the importance of the family context, key conditions that set the stage for conflict, and essential contributing factors. Implications for routine assessment and screening to identify families at risk and recommendations for future research are highlighted. http://www.jpsmjournal.com/article/S0885-3924(15)00168-2/abstract

Teaching health care providers to provide spiritual care: A pilot study

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 April 2015 – Participants rated their ability to provide R/S [religious/spiritual] care and comfort with religious language as "fair." In the previous two weeks, they reported approximately two R/S patient conversations, initiated R/S conversations less than twice, and prayed with patients less than once. Post-training participants' reported ability to provide spiritual care increased by 33%. Their comfort using religious language improved by 29%, and frequency of R/S care increased. Participants reported having 61% more R/S conversations and more frequent prayer with patients... Confidence in providing spiritual care improved by 36% overall, by 20% with religiously concordant patients, and by 43% with religiously discordant patients. <u>http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0306</u>

Noted in Media Watch, 25 August 2014, #372 (p.16):

 JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 18 August 2014 – 'Limits and responsibilities of physicians addressing spiritual suffering in terminally ill patients.' Many patients experience spiritual suffering that complicates their physical suffering at the end of life. It remains unclear what physicians' perceived responsibilities are for responding to patients' spiritual suffering. Most physicians [i.e., study participants] believe that spiritual suffering tends to intensify physical pain and that physicians should seek to relieve such suffering. <u>http://www.jpsmjournal.com/article/S0885-3924(14)00410-2/abstract</u>

N.B. Selected articles on spirituality and end-of-life care noted in past issues of Media Watch are listed in this issue of the weekly report.

Of related interest:

BMC PALLIATIVE CARE | Online – 15 April 2015 – 'What do I do? Developing a taxonomy of chaplaincy activities and interventions for spiritual care in intensive care unit palliative care.' Chaplains are increasingly seen as key members of interdisciplinary palliative care teams, yet the specific interventions and hoped for outcomes of their work are poorly understood. This project served to develop a standard terminology inventory for the chaplaincy field, to be called the chaplaincy taxonomy. http://www.biomedcentral.com/content/pdf/s12904-015-0008-0.pdf

Hearing loss in palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 April 2015 – Age-related hearing loss is remarkably common, affecting more than 60% of adults over the age of 75. Moreover, hearing loss has detrimental effects on quality of life and communication, outcomes that are central to palliative care. Despite its high prevalence, there is remarkably little written on the impact of hearing loss in the palliative care literature. The authors describe simple methods of screening patients for hearing loss, and suggest that practical approaches should be used universally in patient encounters. These include facing the patient, pitching one's voice low, using a pocket talker, and creating a hearing-friendly environment when planning a family or group meeting. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0367

Selected articles on hearing loss in patients living with a terminal illness noted in past issues of Media Watch:

HEARING JOURNAL, 2015;68(1):18-22. 'Dying to be heard: Hearing healthcare at the end of life.' Good hearing healthcare is essential for people facing the end of life, and yet it often goes overlooked by care providers and families focused on other medical, financial, social, legal, and additional concerns... [Noted in Media Watch, 29 December 2014, #390 (p.7)] http://journals.lww.com/thehearingjournal/Fulltext/2015/01000/Dying to Be Heard Hearing Healthcare at the End.1.aspx

Cont.

- JOURNAL OF PALLIATIVE CARE, 2012;28(2):105-112. 'Palliative and end-of-life care in Newfoundland's deaf community.' Key findings [of this Canadian study] indicate the deaf community has limited understanding of their options for palliative and end-of-life care. [Noted in Media Watch, 13 August 2012, #266 (p.6)] <u>http://www.ncbi.nlm.nih.gov/pubmed/22860383</u>
- HEC FORUM, 2002;14(3):197-208. 'American Sign Language and end-of-life care: Research in the deaf community.' The authors describe a community-based participatory research process used to develop a means of discussing end-of-life care needs of deaf seniors. [Noted in Media Watch, 20 August 2012, #267 (p.12, under 'Worth Repeating')] http://link.springer.com/article/10.1023/A%3A1020508511133

The population burden of chronic symptoms that substantially predate the diagnosis of a life-limiting illness

JOURNAL OF PALLIATIVE MEDICINE Online - 10 April 2015 - Many people in our communities live with symptoms for years or decades, something of relevance to hospice/palliative care clinicians and researchers. The proportion of people in the community at large who have a chronic symptom is likely to approximate the proportion of people referred to hospice/palliative care services with that same chronic symptom that pre-dates their life-limiting illness. Such patients may have different responsiveness to, and expectations from, symptomatic therapies, thus requiring more advanced approaches to symptom control. For researchers evaluating the impact of hospice / palliative care services, failing to account for people with long-term refractory symptoms predating their life-limiting illness may systematically underestimate services' benefits. Observational symptom prevalence studies reported in hospice/palliative care to date have not accounted for people with longterm refractory symptoms, potentially systematically overestimating symptoms attributed to life-limiting illnesses. Cross-sectional community prevalence rates of key chronic refractory symptoms largely unrelated to their life-limiting illness reflect the likely prevalence on referral to hospice/palliative

Of related interest:

Critique of published research

Update on hospice and palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 April 2015 – The goal of this update ... is to summarize and critique research published between 1 January and 31 December 2013 that has the highest potential for impact on clinical practice. The authors ranked ... articles based on study quality, scientific merit, topic area, appeal to breadth of interest, and potential for impact on the clinical practice. The authors summarize the findings of eight articles with the highest ratings, and make recommendations for clinical practice based on the strength of the result evident. http://online.liebertpub.com/doi/abs/10.1089/jpm. 2015.0070

care... Research is needed to establish the prevalence and severity of chronic symptoms that pre-date the diagnosis of a lifelimiting illness in people referred to hospice/palliative care services, comparing this to whole-of-population estimates; and, 2) whether this group is disproportionately represented in people with refractory symptoms.http://online.liebertpub.com/doi/abs/10. 1089/jpm.2014.0444

 PLOS ONE | Online – 14 April 2015 – 'Measuring intensity of end-of-life care: A systematic review.' This review is the first to attempt to identify measures used specifically for evaluating intensity of end-of-life care. It provides a synthesis for choosing measures based on their previous use but also highlights the crucial need for more validation studies... http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0123764

Dying in the age of choice

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2015;11(1):27-49. Due to the unprecedented increase in the U.S. aging demographics, many more people are living longer and reaching older ages than ever before. However, a longer life is not necessarily a better life, as the vast majority will face a period of prolonged deteriorating health prior to death. Although notable efforts have been underway that are designed to improve the end-of-life experience, increasing numbers of individuals express a desire and/or act upon an intent to end their lives precipitously. Though still limited, the options to actively participate in their own deaths are growing. Requests for a hastened death can occur among people of all ages and includes those with advanced illness as well as others wanting to die due to unbearable suffering. This article provides an overview of the ongoing discourse about the experience of dying faced by many older adults... The limitations of established practices which seek to provide a "better" dying experience are identified followed by discussion of the growing availability of alternative options. Reflective considerations are presented to guide practice *vis-à-vis* the changing landscape surrounding options in dying. http://www.tandfonline.com/doi/abs/10.1080/15524256.2015.1021072#.VTERPmdFCos

Paediatric palliative care: There is always more we can do

PAEDIATRICS & CHILD HEALTH, 2015; 20(3):123-124. A noticeable shift in both acuity and complexity has occurred in the care of ill children over the past decades. Children with conditions that previously required intensive care are now routinely cared for on the wards of our paediatric hospitals; those who once need supervision in a tertiary care centre with each deterioration are now commonly admitted to community hospitals; and, children whose health needs at one time forced them to reside in group homes or institutions are now living at home with their families. Enhancements in our ability to address acute medical problems and advances in medical technology have resulted in a growing number of children who live with their complex conditions. These children should rightly be viewed as part of the success of modern paediatric health care; however, to stop there is to tell only one part of the story. The number of technology-dependent medically fragile children account for a large and growing proportion of hospital admissions. They are living longer, but many still have conditions considered to be life-threatening, if not lifelimiting, in nature. And unfortunately, our ability to improve the quality of life for many of these children, and their families, has not been as remarkable as our achievements in extending the duration of life. <u>http://www.pulsus.com/journals/abstract.jsp?</u> <u>sCurrPg=abstract&jnlKy=5&atlKy=13369&is</u> <u>uKy=1255&isArt=t&fromfold=Current+Issue</u> <u>&fold=Abstract</u>

N.B. Click on 'Full-Text PDF' for complete editorial.

Paediatric palliative care in Canada: A national survey of paediatricians

PAEDIATRICS & CHILD HEALTH, 2015;20(3): 153-154. Canadian paediatricians care for a large number of children with varying palliative care needs. Enhanced exposure to palliative care during residency training and continuing education programs would be beneficial to ensure paediatricians are aware that palliative care is meant to offer the best possible quality of life for children with life-threatening conditions and their families. Educational opportunities may include topics such as palliative medicine, grief and loss, decisions to forego life-sustaining medical treatments, and spiritual dimensions of life and illness. http://www.cpsp.cps.ca/uploads/publications/High lights-paediatric-palliative-care.pdf

N.B. This issue of *Paediatrics & Child Health*, the journal of the Canadian Paediatrics Society, focuses on palliative care for children living with a life-threatening or life-limiting illness. Contents: <u>http://www.pulsus.com/journals/toc.jsp?sCurrPg=journal&jnlKy=5&fold=Current%20Issue&utm_source=eTOC&utm_medium=email&utm_content=Header%20TOC%20link&utm_campaign=PCH_2_0_3</u> Of related interest:

 NURSING CHILDREN & YOUNG PEOPLE, 2015;27(3):6. 'Framework on decision making about end-of life-care updated.' Situations where it may not be in a child's best interests to continue treatment if it cannot prolong life are outlined in an updated framework for practice, which aims to minimise suffering and deal with crucial ethical issues in end of life care. http://journals.rcni.com/doi/full/10.7748/ncyp.27.3.6.s3

Balancing cure with comfort: Palliative care in critical care

PALLIATIVE MEDICINE, 2015;29(4):288-290. While critical care has historically been perceived as the antithesis of palliative care, there is growing recognition that these two clinical specialties offer important complementary skills. Both can claim that they were founded in the early 1950s, when intensive ventilator units were established to support patients suffering from respiratory failure caused by the polio epidemics sweeping Europe and North America, while Cicely Saunders was starting her training in medicine to deliver her vision of compassionate and effective palliative care for those nearing the end of their lives. Critical and palliative care have gradually converged in clinical practice, research and quality initiatives to focus on the transition from saving lives to easing the burden of terminal critical illness. This convergence has been fostered by several factors. Critical care units have progressed from delivering single system support measures to providing complex multisystem interventions for patients with multiple organ failure, many of whom would not have survived 40 years ago. At the same time, critical care units have become a common final destination before death for the increasing proportion of the frail elderly with multi-morbidity, who might, with prior knowledge, have chosen an alternative care with fewer interventions... pathwav http://pmj.sagepub.com/content/29/4/288.ext ract

Practices of end-of-life decisions in 66 southern French ICUs 4 years after an official legal framework: A 1-day audit

ANAESTHESIA CRITICAL CARE & PAIN MEDI-CINE | Online - 7 April 2015 - Since the implementation of two French laws in 2002 and 2005, and the implementation of guidelines about endof-life (EoL) decisions, few studies concerning EoL practices in French intensive care units (ICUs) have been reported. This study was aimed at assessing compliance with recommendations and current legislation concerning EoL decisions. The written designation of a surrogate decisionmaker was reported for 87 (15%) patients. Advance directives were completed for only 4% of patients. The EoL decision-making process consisted in a multidisciplinary approach for 99 (47%) patients and was recorded in the medical chart for 63 (64%) cases. Families were informed about medical decisions in 58% of cases. This proportion was higher (87%) if a decision to forego life-sustaining therapy was made. EoL decisions consisted of withholding treatments for 72 (94%) patients and withdrawal of treatments for 5 (6%) patients. The major finding ... is the existence of a gap between the widely approved EoL recommendations ... and the daily practice of southern French ICUs. Even if EoL decisions are mostly shared with relatives, their written documentation in medical charts remains insufficient. Concerning EoL practices, the withdrawal of treatment remains an uncommon decision. http://www.sciencedirect.com/science/article/pii/S 2352556815000430

Assisted (or facilitated) death

Representative sample of recent news media coverage:

CANADIAN FAMILY PHYSICIAN, 2015;61(4):314-316. 'Is physician-assisted death in anyone's best interest? Yes.' I will make 2 arguments to support the idea that assisted death is in the best interests of some patients: death can sometimes be in a patient's best interest; and capable patients are well positioned to determine when death is in their best interests. I will then argue that physicians should have a role in assisted death by reversing the premise of this debate and arguing that nobody's interests are served by denying patients the right to physician-assisted death. http://www.cfp.ca/content/61/4/314.full

Cont.

- CANADIAN FAMILY PHYSICIAN, 2015;61(4):316-318. 'Is physician-assisted death in anyone's best interest? No.' The issue of physician-assisted death is complex and emotional, and we must not allow truth to become a casualty. Medical professionals and laypersons alike struggle to understand distinctions between euthanasia and physician-assisted suicide, and many more fail to distinguish either act from simple refusal or authorized withdrawal of treatment. We must demand and demonstrate a courageous and respectful clarity. http://www.cfp.ca/content/61/4/316.full
- DIVERSITY AND EQUALITY IN HEALTH AND CARE, 2015;12(1):4-5. 'Children and euthanasia: Belgium's controversial new law.' On 13 February 2014 Belgium amended its law to extend the right to request euthanasia to terminally ill children. Despite strong opposition from some medical professionals and religious groups the law was passed on a vote of 86 to 44 (with 12 abstentions). Out of the three European countries that permit voluntary euthanasia Belgium has become the first to remove all reference to an age restriction. In the Netherlands, by comparison, children must be over the age of 12 whereas similar laws in Luxembourg apply only to adults. http://diversityhealthcare.imedpub.com/children-and-euthanasia-belgiums-controversial-new-law.pdf

Media Watch Online International INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/aboutiahpc/newsletter/2015/04/media-watch/#lived INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://www.ipcrc.net/archive-global-palliative-carenews.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-andpalliative.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/updates/international-palliative-care-resourcecenter-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 | HPC Consultation Services (Waterloo Region/Wellington County): <u>http://hpcconnection.ca/general-resources/in-the-news/</u>

ONTARIO | Palliative Care Consultation Program (Oakville): <u>http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/</u> [Scroll down to 'Additional Resources']

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <u>http://www.eapcnet.eu/Themes/Organization/Links.aspx</u> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <u>http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes</u>

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

Worth Repeating

2010 ranking of end-of-life care across the world

ECONOMIST INTELLIGENCE UNIT | Online - 2010 - 'The quality of death: Ranking end-of-life care across the world.' While few would argue against the need for more funding for end-of-life care, money is not the only barrier to the accessibility and quality of that care. Many factors hamper progress in this field - from cultural taboos and lack of understanding of end-of-life care, to the geographic dispersal of populations in some countries and the futile use of life-preserving medical technologies in places such as the U.S. Of course, sufficient funding is important, particularly in developing countries where scarce financial resources and the magnitude of competing problems means there is often little money left with which to pay for hospice and palliative care services. High-level political commitment also plays a vital role, as long as it is matched with coordinated policy. Legislation improving access to opioids - as well as instruction for physicians and community workers in their administration - will be crucial if millions around the world are not to be left to die in agony. A strategy without access to basic drugs will not help those needing care. Technology, too, may help doctors manage their patients' conditions remotely, allowing more people to stay at home for longer. However, the human factor should not be underestimated, for end-of-life care is about far more than medical treatments and painkillers. Certainly, a lack of trained doctors and nurses is one impediment to improving quality of death. But end-of-life care must be a multi-disciplinary effort. Complex psychological problems arise when death is in view, particularly when it comes to the death of children. And counselling is necessary not only for the dying, but also for their families, requiring sensitive personal care that extends beyond death, through the grieving process. The cost of such services is hard to measure in numbers or in dollars. This presents problems when it comes to funding models, particularly in the U.S. where the current healthcare system rewards medical providers for procedures rather than outcomes and hospices are paid on a daily basis, usually regardless of length of care. As more and more people spend longer living with chronic illness, the challenge will be to come up with payment models that reflect this. Governments and providers are in a race against time however quickly they can beef up their end-of-life care infrastructure,



they may still not be able to meet the even faster pace at which their citizens are reaching an age or condition where they need those services. So while calls echo around the world for end-of-life care to become enshrined in national and international policy as a human right, the reality is that – even if it achieves that status – for much of the world's population, such a commitment will exist on paper only. <u>http://graphics.eiu.com/upload/QOD main final edition Jul12 toprint.pdf</u>

N.B. *The Quality of Death: Ranking End of-life-Care Across the World* was commissioned by The Lien Foundation, of Singapore, and published by the Economist Intelligence Unit, July 2010. [Noted in Media Watch, 19 July 2010, #158 (p.3)]

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. <u>http://www.pcn-e.com/community/pg/file/owner/MediaWatch</u>

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.

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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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