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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Compiled & Annotated by Barry R. Ashpole

End-of-life care in the community: Scroll down to <u>Specialist Publications</u> and 'Transferring critically ill patients home to die: Developing a clinical guidance document' (p.12), in *Nursing in Critical Care*.

Canada

Hospice beds waiting for funding

ALBERTA | St. Albert Gazette - 4 March 2015 - St. Albert is a city of more than 60,000 people and nearly 20,000 more live in Sturgeon County - yet there's still only one hospice bed to serve that entire population. Alberta Health has established a benchmark that indicates there should be 7.7 palliative beds per 100,000 population... There should be at least six beds for the St. Albert and Sturgeon service area, but even the Edmonton area is lacking, only 64 beds for a combined population of close to 1.2 million, and only one of those beds is north of Norwood. Calgary, in contrast, has more than 100 beds for its 1.1 million residents. http://www.stalbertgazette.com/article/20150 304/SAG0801/303049986

Specialist Publications

'Impacts of care-giving and sources of support: A comparison of end-of-life and non-end-of-life caregivers in Canada' (p.10), in Health & Social Care in the Community.

'Diversity in rural communities: Palliative care for the Low German Mennonites' (p.10), in Journal of Rural & Community Development.

Ontario pledges palliative care teams for patients wishing to die at home

ONTARIO | The Globe & Mail – 2 March 2015 – For nearly two years, Darren Cargill, a palliative medicine specialist in Windsor, Ontario, has been waiting for the money that he and his team of doctors and nurses were promised to provide round-the-clock support to gravely ill patients who want to die in their own homes. On Monday, he finally received an e-mail from the provincial government saying the funding – \$172,000 per year for the whole team – would begin to flow within

Cont.

60 days, retroactive to 1 April 2013. The e-mail arrived in Dr. Cargill's inbox after *The Globe & Mail* began asking questions about the pay delay late last week and after *The Windsor Star* highlighted the issue in a column accusing the province of incompetently managing an experiment in community palliative care that the Auditor-General had praised in her most recent report. The ministry came to us in April of 2013 and said we could go forth and start providing this care and we could sort out the details afterward," said Dr. Cargill, a palliative physician at the Hospice of Windsor & Essex County. "That's where the story starts." The story actually begins even earlier than that, with Dr. Cargill and his fellow palliative care specialists trying to solve a thorny problem: How can the health-care system help more people to die comfortably at home? http://www.theglobeandmail.com/life/health-and-fitness/health/ontario-pledges-palliative-care-teams-for-patients-wishing-to-die-at-home/article23256223/

- 'Another sad tale of incompetence,' The Windsor Star, 20 February 2015. [Noted in Media Watch, 2 March 2015, #399 (p.1)] http://blogs.windsorstar.com/opinion/chris-vander-doelen-another-sad-tale-of-incompetence
- '2014 Report of the Office of the Auditor General of Ontario (Chapter 3: Ministry of Health & Long Term Care – Palliative Care, pp.258-288),' 9 December 2014. [Noted In Media Watch, 15 December 2014, #388 (p.2)] http://www.auditor.on.ca/en/reports-en/en14/308en14.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE GLOBE & MAIL | Online Accessed 8 March 2015 'When will the law change to decriminalize doctor-assisted deaths?' No later than 2 February 2016. In a legal sense, Parliament could just do nothing; politically, though, that is highly unlikely, as the Conservative government would be seen as abdicating its duty to Canadians. If Parliament approves no new law on assisted death by next 6 February, the law would change on that date to permit assisted dying for some suffering adults. https://ask.theglobeandmail.com/when-will-the-law-change-to-decriminalize-doctor-assisted-deaths/
- ONTARIO | The National Post 6 March 2015 'Doctors who refuse to provide services on moral grounds could face discipline under new Ontario policy.' Moral or religious convictions of a doctor cannot impede a patient's access to care, the College of Physicians & Surgeons of Ontario said in a 21-3 vote supporting an updated Professional & Human Rights policy. While it does not address physician-assisted death, it could set the stage for conflict with the Canadian Medical Association, whose leaders want to protect doctors against "mandatory referral" when the Supreme Court ... ruling legalizing doctor-hastened dying takes effect... http://news.nationalpost.com/2015/03/06/doctors-who-refuse-to-provide-services-on-moral-grounds-could-face-discipline-under-new-ontario-policy/
- THE NATIONAL POST | Online 5 March 2015 'Unacceptable to force doctors to participate in assisted dying against their conscience: CMA head.' No physician in the country should be forced to play a role in any aspect of assisted dying against their moral or religious beliefs including referring patients to another doctor willing to help them die, the Canadian Medical Association says. http://news.nationalpost.com/2015/03/05/unacceptable-to-force-doctors-to-participate-in-assisted-dying-against-their-conscience-cma-head/
- BRITISH COLUMBIA | The Province (Vancouver) 3 March 2015 'Family of Alzheimer's patient loses right-to-die case despite living will.' The B.C. Court of Appeal has dismissed a bid from the family of an Alzheimer's patient who were arguing she is being kept alive in a care home against her will. Justice Mary Newbury said in a written ruling that 83-year-old Margaret Bentley is exercising her consent when she opens her mouth to accept food and water. http://www.theprovince.com/Family+Alzheimer+patient+loses+right+case+despite+living+will/10858017/story.html

U.S.A.

Dying inmates may appeal court decisions against early release

CALIFORNIA | The Los Angeles Times - 5 March 2015 - The California Supreme Court decided unanimously ... dying prisoners may appeal a judge's decision refusing them an early release. The ruling overturned an appeals court decision that said only the Department of Corrections & Rehabilitation or the parole board could challenge a trial court's decision denying a so-called compassionate release. Alden Loper, the severely ill inmate who challenged the denial, was charged ... with underpayment of taxes and worker's compensation premiums in his tree trimming business. He pleaded guilty to one charge and was sentenced in February 2011 to six years in prison. In August 2012, the Corrections Department asked a court to release Loper because he was terminally ill. A prison doctor said Loper suffered from a variety of ailments and might die within six months. A judge in San Diego asked the department for more information. Another prison doctor said Loper had a terminal illness, but the second doctor could not say with certainty Loper would die within six months. A state requirements for compassionate release is that the inmate has fewer than six months to live. The judge turned down the Corrections Department's request. http://www.latimes.com/local/lanow/la-me-In-dying-prisoners-20150305-story.html

Specialist Publications

'Essential elements of an effective prison hospice program' (p.7), in American Journal of Hospice & Palliative Medicine.

U.S. faces 90,000 doctor shortage by 2025, medical school association warns

THE WASHINGTON POST | Online – 3 March 2015 – The U.S. faces a shortage of as many as 90,000 physicians by 2025, including a critical need for specialists to treat an aging population that will increasingly live with chronic disease, the association that represents medical schools and teaching hospitals reported... The nation's shortage of primary care physicians has received considerable attention in recent years, but the Association of American Medical Colleges [AAMC] report predicts that the greatest shortfall, on a percentage basis, will be in the demand for surgeons – especially those who treat diseases more common to older people, such as cancer. In addition to the growing and aging population, full implementation of the Affordable Care Act in all 50 states would increase demand for doctors as more people are covered by insurance. The AAMC represents all 141 U.S. medical schools and 17 in Canada, as well as 400 major teaching hospitals and health systems, including 51 Department of Veterans Affairs medical centers. http://www.washingtonpost.com/news/to-your-health/wp/2015/03/03/u-s-faces-90000-doctor-shortage-by-2025-medical-school-association-warns/

'The Complexities of Physician Supply and Demand: Projections from 2013-2025,' Association
of American Medical Colleges, March 2015. The first comprehensive national analysis that
takes into account both demographics and recent changes to care delivery and payment
methods. https://www.aamc.org/download/426242/data/ihsreportdownload.pdf

Noted in Media Watch, 24 November 2014, #385 (p.11):

ONCOLOGY TIMES | Online – 14 November 2014 – 'Nearly half of palliative care clinicians plan to exit the field within a decade.' One in four [of the palliative care clinicians surveyed] say there is a good chance that they will leave by 2018. While retirement is the most common reason palliative care specialists are planning to leave, many survey respondents cited burnout as one of the reason they are considering their exit. http://journals.lww.com/oncology-times/blog/asco11spotlightnews/pages/post.aspx?PostID=167

Noted in Media Watch, 16 July 2012, #262 (p.10):

- HEALTH LEADERS | Online 13 July 2012 'Palliative care challenged by physician shortage.' While there is about one cardiologist [in the U.S.] for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a ... life-threatening illness. http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage
 - 'Estimate of current hospice and palliative medicine physician workforce shortage,' Journal of Pain & Symptom Management, 2012;40(6):899-911 [Noted in Media Watch, 13 December 2010, #179 (p.9)] http://www.jpsmjournal.com/article/S0885-3924(10)00602-0/abstract

If patients only knew how often treatments could harm them

THE NEW YORK TIMES | Online – 2 March 2015 – Despite the existence of metrics to help patients appreciate benefits and harms, a systematic review suggests our expectations are not consistent with the facts. Most patients overestimate the benefits of medical treatments, and underestimate the harms; because of that, they use more care. The study is the first to systematically review the literature on accuracy of patients' expectations of benefits and harms of treatment. http://www.nytimes.com/2015/03/03/upshot/if-patients-only-knew-when-more-information-means-less-treatment.html?ref=health% r=0

'Patients' expectations of the benefits and harms of treatments, screening, and tests,' JAMA Internal Medicine, 2015;175(2):274-286. The authors systematically reviewed all studies that have quantitatively assessed patients' expectations of the benefits and/or harms of any treatment, test or screening test. http://archinte.jamanetwork.com/article.aspx?articleid=2038981

Hospice project gives students rare insight into the end of life

MAINE | The Portland Press Herald – 1 March 2015 – Kelly McVan and Caitlyn Farrell got an early glimpse of what they would experience over the next 48 hours. Soon after arriving at Gosnell Memorial Hospice House for a rare educational experience, the two University of New England medical students sat by a window and witnessed a deceased patient being removed from the facility by a funeral director. Several hospice staff members lined the snowy walkway as the body was wheeled out to a dark hearse. They hugged the patient's loved ones and said goodbye. Some staff members wiped away tears. It was an unexpected and emotional moment for the two young medical students, watching quietly during their orientation in a small conference room. http://www.pressherald.com/2015/03/01/hospice-project-gives-students-rare-insight-into-the-end-of-life/

Noted in Media Watch, 19 August 2013, #319 (p.19):

■ THE ATLANTIC | Online – 12 August 2013 – 'Medicine's most important teachers.' Canadian Sir William Osler once said that medical education at its best "begins with the patient, continues with the patient, and ends with the patient." In other words, no matter how knowledgeable and skilled our medical school faculty members, medical education centers less on what the teachers seek to teach than on what patients need future physicians to learn. http://www.theatlantic.com/health/archive/2013/08/medicines-most-important-teachers/278573/

Assisted (or facilitated) death

Representative sample of recent news media coverage:

UTAH | KSL News (Salt Lake City) – 6 March 2015 – 'Right-to-die bill put on hold for further study.' Utah lawmakers put on hold a legislative proposal that would have created a process to allow terminally ill Utahns to obtain prescription medication they could self-administer "for a humane and dignified death." After hearing emotional testimony on both sides on the proposed Utah Death with Dignity Act, the House Health & Human Services Committee voted to refer the issue to interim study. http://www.ksl.com/?nid=757&sid=33715608

International

Elder care in the U.K.

Elderly must get 30-minute home care visits carers told: New rules introduced to end scandal of drive by appointments

U.K. | *The Daily Mail* – 5 March 2015 – Updated guidance ... insists that calls last for at least 30 minutes if they are offering personal care such as washing or dressing. The advice, published by National Health Service spending watchdog National Institute for Health & Care Excellence, said 15-minute drop-ins should only be considered in certain cases such as checking if someone has taken their medication. In a sign of how bad things have become, guidelines ... spell out the care offered to the elderly – telling home helps to leave enough time to "talk to the person." Care workers are also reminded to treat people with "empathy, courtesy, respect and in a dignified way." http://www.dailymail.co.uk/news/article-2980144/Elderly-30-minute-home-care-visits-carers-told-New-rules-introduced-end-scandal-drive-appointments.html

Noted in Media Watch, 23 February 2015, #398 (p.6):

U.K. (England) | The Telegraph – 15 February 2015 – 'More than 500,000 home care visits last less than five minutes.' Minister of Care & Support Norman Lamb has called for a "fundamental" overhaul of home help services after an investigation, based on figures obtained under the Freedom of Information Act, exposed that more than half a million visits last less than five minutes each. http://www.telegraph.co.uk/news/health/news/11302534/Revealed-more-than-500000-home-care-visits-last-less-than-five-minutes.html

Noted in Media Watch, 2 February 2015, #397 (p.7):

- U.K. (England) | The Daily Mail 31 January 2015 'Indignity, a dearth of compassion, terrible suffering and utter chaos...' An investigation by The Daily Mail has revealed a catalogue of failings inadequate training, call times of 15 minutes or even less in which carers must meet their clients' most basic needs... It all adds up to a grim picture, according to the former care and support minister Paul Burstow. http://www.dailymail.co.uk/news/article-2933902/Indignity-dearth-compassion-terrible-suffering-utter-chaos-investigation-II-terrify-family-lay-bare-agonising-death-Britain-s-home-care-system.html
 - 'Key to Care: Report of the Burston Commission on the Future of the Home Care Workforce,' Local Government Information Unit, December 2014. http://www.lgiu.org.uk/wp-content/uploads/2014/12/KeyToCare.pdf

New poll reveals concerns over cancer treatment in Northern Ireland

U.K. (Northern Ireland) | *The Belfast Telegraph* – 3 March 2015 – Seven out of 10 people in Northern Ireland have concerns over how the pain of a terminally ill loved one would be managed during cancer treatment, a new survey has revealed. The Marie Curie poll showed that 45% of Northern Ireland respondents would also be worry that a loved one would not have access to round-the-clock care and support if diagnosed with a terminal illness. The survey conducted across the U.K., asked people about the types of worries they would have if faced with having to care for a loved one. In Northern Ireland 69% of respondents said they would be concerned that pain resulting from the illness would not be managed correctly. This compared to 51% in England, 45% in Scotland and 42% in Wales. http://www.belfasttelegraph.co.uk/news/northern-ireland-31035292.html

 'Marie Curie: U.K. Public Opinion on Taking Care of a Loved One with a Terminal Illness,' ComRes, 2 March 2015. http://comres.co.uk/wp-content/uploads/2015/02/Marie-Curie-Terminal-Illness-Survey.pdf

What do doctors say to "alternative therapists" when a patient dies? Nothing. We never talk

U.K. | *The Guardian* – 2 March 2015 – Research shows that nearly 70% of cancer patients and a staggering 90% of patients enrolled in an early phase clinical trial use alternative therapies. We now know that many of these therapies are not only unhelpful but are downright dangerous. Herbs and supplements can interact with chemotherapy and reduce its efficacy, a real drawback when therapy is given with curative intent. Oncologists and alternative health practitioners move in different spheres though plenty of evidence suggests we end up looking after the same patients. When I discover (usually belatedly) that my patient endured the broken promise of an unproven cure, I feel dejected. The more expensive, extreme or exotic the treatment the messier seems the ending. Health literacy moves at a very slow pace. The alternative health industry, worth many billions of dollars, marches briskly. It will always attract unguarded patients who will cling to the faintest promise of recovery without associated harm. Whenever money changes hands and the premise sounds too good to be true, the motto remains: *Caveat Emptor*. http://www.theguardian.com/commentisfree/2015/mar/03/what-do-doctors-say-to-alternative-therapists-when-a-patient-dies-nothing-we-never-talk

Noted in Media Watch, 24 January 2011, #185 (p.4):

U.S. | U.S. News & World Report – 19 January 2011 – 'Many U.S. hospices provide alternative therapies: Report.' Research suggests although complementary and alternative therapies are not commonly covered by medical insurance, these services can help improve a critically ill patient's quality, alleviating symptoms of pain and anxiety, helping to provide comfort. http://health.usnews.com/health-news/family-health/pain/articles/2011/01/19/many-us-hospices-provide-alternative-therapies-report

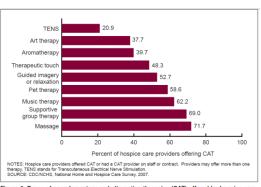


Figure 2. Types of complementary and alternative therapies (CAT) offered by hospice care providers: United States, 2007

 'Complementary and Alternative Therapies in Hospice: The National Home & Hospice Care Survey (U.S. 2007), National Health Statistics Reports, No. 33, 19 January 2011. http://www.cdc.gov/nchs/data/nhsr/nhsr033.pdf

End-of-life care in England

Every Moment Counts: A new vision for coordinated care for people near the end of life calls for brave conversations

U.K. (England) | National Council for Palliative Care – 2 March 2015 – Every Moment Counts sets out how good, coordinated – or integrated – care looks to people near the end of life and is written from their point of view. This new report draws on surveys, testimonies of bereaved carers, experiences of end-of-life care charities, and reflections of professionals that highlighted failures in coordinating and personalising the different elements of end-of-life care. Highlighted is that individuals working to support and care for the person are often generalists who may not have the confidence – or the training and preparation – to open up conversations about choices and preferences. Every Moment Counts shows these are vital to the people and carers in question.



http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/every moment counts publication with links.pdf

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

Building new teams for late life care: Lessons from LifeCourse

AMERICAN JOURNAL OF HOSPITAL & PALLIATIVE MEDICINE | Online – 5 March 2015 – This article details team development within a longitudinal cohort study designed to bring team-based, whole person care early in the course of serious illness. The primary innovation of this approach is the use of non-clinically trained care guides who support patients and family members by focusing care around what matters most to patients, linking to resources, collaborating with other providers, and offering continuity through care transitions. By describing the development of this team, we document the kinds of questions others may ask during the process of team creation. http://ajh.sagepub.com/content/early/2015/03/03/1049909115574692.abstract

Essential elements of an effective prison hospice program

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online - 2 March 2015 - As the number of prison inmates facing end-stage chronic illness grows, more prisons across the U.S. must address the need for end-of-life care. Many will likely need to develop a plan with potentially limited resources and external support. This case study presents one long-running model of care, the Louisiana State Penitentiary Prison Hospice Program. Based on field observations and in-depth interviews with hospice staff, inmate volunteers and corrections officers, we identify five essential elements that have contributed to the long-term operation of this program: patient-centered care. an inmate volunteer model, safety and security, shared values, and teamwork. The authors describe key characteristics of each of these elements, discuss how they align with earlier recommendations and research, and show how their integration supports a sustained model of prison end-of-life care. http://ajh.sagepub.com/content/early/2015/02/27/1049909115574491.abstract

Prison Hospice Backgrounder

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons

Noted in Media Watch, 16 February 2015, #397 (p.10):

EARLY CAREER ACADEMIC NETWORK BULLETIN (Howard League for Penal Reform) | Online – January 2015 – 'Planning for the end of life in prison.' Research underway at Lancaster University is investigating how palliative and end-of-life care is provided for prisoners likely to die from natural causes whilst still in custody. This article explores some of the complexities inherent in providing palliative care in a prison setting, and considers early findings from research which suggests ways to improve end-of-life care for this group of prisoners. https://d19ylpo4aovc7m.cloudfront.net/fileadmin/howard_league/user/pdf/Research/ECAN/ECAN/bulletin_25.pdf#page=10

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

Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care

CHEST | Online - 5 March 2015 - The tendency toward "either/or" thinking (either cure or comfort) in traditional biomedical care paradigms does little to optimize care in advancing chronic illness. Calls for improved palliation in chronic lung disease mandate a review of related care gaps and current clinical practices. While specialist palliative services have their advocates, adding yet another element to an already fragmented, often complex care paradigm will be a challenge. Instead the authors propose a more holistic, patient-centred approach based on elements fundamental to palliative and best care practices generally and integrated as needed across the entire illness trajectory. To support this approach they review the concept of primary palliative care competencies, identify vulnerability specific to those living with advanced COPD (an exemplar of chronic lung disease), and describe the need for care plans shaped by patient-centred communication, timely palliative responsiveness, and effective advance care planning. A costly systemic issue in the management of chronic lung disease is patients' increasing dependency on episodic emergency room care to deal with preventable episodic crises and refractory dyspnea. The authors address this issue as part of a proposed model of care that provides pro-active, collaborative case management and the appropriate and carefully monitored use of opioids. http://journal.publications.chestnet.org/article.aspx?articleid=2195111&resultClick=3

Noted in Media Watch, 10 November 2014, #383 (p.12):

■ EUROPEAN RESPIRATORY JOURNAL | Online – 30 October 2014 – 'The lung cancer patient, the pneumologist and palliative care: A developing alliance.' Considerable evidence is now available on the value of palliative care for lung cancer patients in all stages and at all times during the course of the disease. However, pneumologists and their institutions seem to be widely in arrears with the implementation of palliative care concepts and the development of integrated structures. This review focuses on the available evidence and experience of various frequently unmet needs of lung cancer patients, especially psychological, social, spiritual and cultural ones. http://erj.ersjournals.com/content/early/2014/10/30/09031936.00072514.abstract

Noted in Media Watch, 27 May 2013, #307 (p.8):

■ THE LANCET RESPIRATORY MEDICINE | Online – 17 May 2013 – 'Palliative care for lung disease: Start early, stay late.' At the end of life when all reasonable curative interventions have failed, many patients with end-stage lung disease still die in pain after much suffering. http://www.thelancet.com/journals/lanres/article/PIIS2213-2600(13)70083-3/fulltext#article_upsell

Public health and palliative care in 2015

CLINICS IN GERIATRIC MEDICINE | Online – 25 February 2015 – Palliative care is a public health concern, because the problems faced by patients and their families represent a substantial burden of illness and cost to the society that is likely to increase markedly in the future as the world's population continues to age. There are also inequities in access to palliative care and continued unmet need. http://www.geriatric.theclinics.com/article/S0749-0690(15)00003-8/abstract

Noted in Media Watch, 23 February 205, #398 (p.9):

GERONTOLOGIST | Online – 17 February 2015 – 'Public health imperative of the 21st Century: Innovations in palliative care systems, services, and supports to improve health and well-being of older Americans.' A primary aim of federal aging and health policy must be promoting innovations in palliative care systems, services, and supports that improve the experience of growing old in America. Older adults must contend with increasing burden over the life course often as the result of life-limiting chronic pain and chronic illnesses... http://gerontologist.oxfordjournals.org/content/early/2015/02/16/geront.gnu178.abstract

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Noted in Media Watch, 15 December 2014, #388 (p.5):

- ANNALS OF INTERNAL MEDICINE | Online 9 December 2014 'Engaging public health in end-of-life issues: It is time to step up to the plate.' This commentary discusses the report from the [U.S.] Institute of Medicine Committee on Approaching Death, 1 noting that it is the first report on the end of life to explicitly mention public health as having a role in this arena and discusses the promise of this approach. http://annals.org/article.aspx?articleid=2020457
 - 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] http://www.iom.edu/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf

Helpful aspects of bereavement counselling: An interpretative phenomenological analysis

COUNSELLING & PSYCHOTHERAPY RESEARCH | Online – 25 February 2015 – Respondents identified five helpful aspects of counselling. First, the independence of the counsellor: that they were outside the family and social network. Second, the counsellor's skilled listening: being attentive, welcoming, demonstrating competence and being "to the point." Third, the non-directivity of the counselling work: being allowed to take the lead and to talk on a range of issues, both bereavement and non-bereavement related. Fourth, having their unhelpful thinking challenged, being encouraged to see things from a broader perspective and through addressing their feelings of guilt and anger. Fifth, by having their responses to bereavement normalised through psychoeducation and therapist self-disclosure. Findings support previous research which suggests both more, and less, directive interventions can be helpful for clients who experience bereavement. http://onlinelibrary.wiley.com/doi/10.1002/capr.12000/abstract?systemMessage=Wiley+Online+Library+will+be+disrupted+on+7th+March+from+10%3A00-13%3A00+GMT+%2805%3A00-08%3A00+EST%29+for+essential+maintenance.++Apologies+for+the+inconvenience.&userlsAuthenticated=false&deniedAccessCustomisedMessage

Of related interest:

JOURNAL OF THE AMERICAN ASSOCIATION OF NURSE PRACTITIONERS | Online – 26 February 2015 – 'Caring for the bereaved parent: Guidelines for practice.' The authors used an extensive review of the literature for original research reports of bereaved parents' self-identified needs for comfort from their friends, family, and healthcare practitioners. Insight gained from the authors' clinical work with bereaved parents added further understanding. Guidelines were created for use by both friends/family members and health professionals. http://onlinelibrary.wiley.com/doi/10.1002/2327-6924.12224/full

Patient-satisfaction surveys on a scale of 0 to 10: Improving health care, or leading it astray?

THE HASTINGS REPORT | Online – 6 March 2015 – The current institutional focus on patient satisfaction and on surveys designed to assess this could eventually compromise the quality of health care while simultaneously raising its cost. The authors begin this paper with an overview of the concept of patient satisfaction, which remains poorly and variously defined. Next, they trace the evolution of patient-satisfaction surveys, including both their useful and problematic aspects. The authors then describe the effects of these surveys, the most troubling of which may be their

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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.13.

influence on the behavior of health professionals. The pursuit of high patient-satisfaction scores may actually lead health professionals and institutions to practice bad medicine by honoring patient requests for unnecessary and even harmful treatments. Patient satisfaction is important, especially when it is a response to being treated with dignity and respect, and patient-satisfaction surveys have a valuable place in evaluating health care. Nonetheless, some uses and consequences of these surveys may actively mislead health care. Our critique of patient-satisfaction surveys takes into consideration three different ways patients may be "satisfied." First is the provision of medically necessary care that actually improves their outcomes. The second concerns interventions that patients or families want but that are medically unnecessary and may negatively affect health outcomes. The third category – comprising factors that are less likely to affect health outcomes but may certainly contribute to a sense of dignity and well-being – includes "humanistic" aspects of health care, such as good communication and treating patients with respect, as well as peripheral aspects, such as convenient parking and designer hospital gowns. These distinctions are important as we explore patient satisfaction and its implications. http://onlinelibrary.wiley.com/doi/10.1002/hast.453/abstract

Impacts of care-giving and sources of support: A comparison of end-of-life and non-end-of-life caregivers in Canada

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 2 March 2015 – This is the second in a series of papers that deal with care-giving in Canada...¹ Building on the first paper, which reviewed the differences between short-term, long-term and end-of-life (EOL) caregivers, this paper uniquely examines the caregiver supports employed by EOL caregivers when compared to non-EOL caregivers (short-term and long-term caregivers combined). The study revealed that with respect to socio-demographic characteristics, health outcomes and caregiver supports, EOL caregivers were consistently worse off. This suggests that although all non-EOL caregivers are experiencing negative impacts from their care-giving role, comparatively greater supports are needed for EOL caregivers. http://onlinelibrary.wiley.com/doi/10.1111/hsc.12205/full

'Differential impacts of care-giving across three caregiver groups in Canada: End-of-life care, long-term care and short-term care,' Health & Social Care in the Community, 31 October 2013. This study provides the evidence for the assertion that EOL care-giving is the most intense type of care-giving, potentially causing the greatest caregiver burden; this is shown through the greater negative impacts experienced by the EOL caregivers when compared with the short-term and long-term caregivers. [Noted in Media Watch, 11 November 2013, #331 (p.8)] http://onlinelibrary.wiley.com/doi/10.1111/hsc.12075/full

End-of-life care in Canada

Diversity in rural communities: Palliative care for the Low German Mennonites

JOURNAL OF RURAL & COMMUNITY DEVELOPMENT, 2014;9(4)246-258. Canada has prided itself in being a multicultural country, but there has been little in-depth examination of cultural or religious diversity in rural settings. This article presents the research related to understanding death and dying among the Low German Mennonites as a case example to illustrate the complexity of providing care to a unique religious group in rural Canada. The findings are presented according to the following: 1) faith-based healthcare facilities; 2) family, community and mutual aid; and, 3) keeping the dying connected. The significance of the findings for the provision of care of this group are also included. file:///C:/Users/Barry/Downloads/JRCD-2014-1128.pdf

Back Issues of Media Watch

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: http://www.ipcrc.net/archive-global-palliative-care-news.php

End-of-life care in France

Continuous sedation until death: How to inform the patient and obtain consent?

MÉDECINE PALLIATIVE | Online - 5 March 2015 - The current French law does not specifically include the issue of information concerning the possibility of continuous sedation until death nor the obtaining of consent in this specific situation. Due to a lack of specific legal documentation. these two elements should be interpreted according to general documentation. The purpose of this article is to debate about two essential elements of the decision-making process for the continuous sedation until death of a patient who is able to express his will: issue of information by the doctor and obtaining consent from the patient. This article is a reflexive interdisciplinary work. First of all, the notion of continuous sedation until death was explained. Then, the current French legal settings concerning the issue of information and the obtaining of consent were presented. Its application for a situation of continuous sedation until death was analysed and discussed. Eventually food for thought was suggested. The issuance of information on the continuous sedation until death is far from being limited to the mechanical application of legislative or regulatory provisions. These provisions, which draw the outlines, raise a number of questions reaching the limits of medical knowledge and most of all of personhood. Human support that is understood as an act of presence in a spirit of open-mindedness, mutual listening and sharing, refusing indifference, seems to be the less worse response to a situation of continuous sedation until death. Beyond the purely legal aspect, the issue of information and the obtaining of consent should first question the physician's ability to listen to his patient and humanly manifest that "the end-of-life is still life." http://www.sciencedirect.com/science/article/pii/S1636652215000100

N.B. French language article.

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.

Metastatic non-small cell lung cancer: A benchmark for quality end-of-life cancer care?

MEDICAL JOURNAL OF AUSTRALIA, 2015;202(3):139-143. The authors sought to establish current patterns of care and use of hospital palliative care for patients with metastatic non-small cell lung cancer in Victoria. In the group studied, which they propose as a benchmark of quality end-of-life care, there was limited use of aggressive treatment measures such as intensive care and chemotherapy at end of life, although high numbers of people died in acute hospitals following a substantial length of stay. Most were referred to palliative care services, but this tended to happen later in the illness course. https://www.mja.com.au/journal/2015/202/3/metastatic-non-small-cell-lung-cancer-benchmark-quality-end-life-cancer-care?0=ip login no cache%3D74b00d8612630ed31c077065791b658d

Transferring critically ill patients home to die: Developing a clinical guidance document

NURSING IN CRITICAL CARE | Online – 28 February 2015 – At a one-day event, stakeholders from cross-community and hospital settings engaged in group work wherein "virtual clinical teams" mapped out, and agreed on, the processes involved in transferring critically ill patients home to die. Factors were identified that promoted and inhibited transfer home and areas in need of development. Eighty-five stakeholders attended the event from across England. The majority strongly agreed transfer of critically ill patients home to die was a good idea in principle. Stakeholders identified "access to care in the community" ... and "unclear responsibility for care of patient" ... as the most important barriers. Consensus was reached on the processes and decision-making required ... and was used to inform content of a clinical practice guidance document. This underwent further refinement following review by 14 clinicians. A ... flow chart was developed. http://onlinelibrary.wiley.com/doi/10.1111/nicc.12169/full

Of related interest:

■ BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 March 2015 – 'Out-of-hours palliative care: what are the educational needs and preferences of general practitioners?' Offering genuine choice to patients over place of care and death requires the provision of high-quality palliative care 24/7. The authors identify that confidence in key palliative care competences is severely lacking. Educational strategies to address this concern must be targeted at GPs preferences for content and mode of delivery. Regular e-learning is favoured, but should be blended with other approaches that promote engagement including out-of-hours themed workshops and case discussion. Specialist palliative care services should engage with out-of-hours providers to support education. http://spcare.bmj.com/content/early/2015/03/05/bmjspcare-2014-000764.abstract

Assisted (or facilitated) death

Representative sample of recent news media coverage:

to physician-assisted suicide in Singapore.' The question of whether a person should have a right to physician-assisted suicide (PAS) has provoked vigorous debates in many Western countries in the courts, legislatures, referenda, and academic literature. As with human rights discourses generally, discourses over PAS cannot be complete or coherent if non-Western countries remain on the periphery. With its common law legal system, particular outlook on human rights, legislation on advance medical directive, and prohibition of attempted suicide and assisted suicide, Singapore presents a valuable case study on whether a right to PAS may be derived from the Singapore Constitution and on the possibilities, merits, and problems that recognition of a right to PAS may present. This article adopts an in-principle inquiry, with reference to case law in England & Wales, Canada, and the U.S., as to whether a person has, or should have, a right to PAS in Singapore in accordance with the constitutional guarantee of the liberty of the person. http://cjcl.oxfordjournals.org/content/early/2015/03/02/cjcl.cxv003.abstract

• CREATIVE NURSING, 2015;21(1):11-14. 'Self-determination, end-of-life decisions, and the role of nurse practitioners.' Nurse practitioners should be aware that societal changes could lead to their being asked to actively assist terminally ill patients who wish to end their lives, as opposed to their current supportive role in palliative care. With physician staff shortages and the need for nurse practitioners to fill the gaps, end-of-life responsibilities could be placed in the hands of nurse practitioners, rather than being reserved for physicians alone. http://www.ingentaconnect.com/content/springer/crnu/2015/000000021/00000001/art00003

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2015/02/media-watch/#CHINESE

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/updates/international-palliative-care-resource-center-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): http://hpcconnection.ca/general-resources/in-the-news/

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

Europe

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

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

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

Barry R. Ashpole Guelph, Ontario CANADA

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'phone: 519.837.8936

e-mail: barryashpole@bell.net