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, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to <u>Specialist Publications</u> and "No decision about me without me" in the context of cancer multidisciplinary team meetings: A qualitative interview study' (p.8), in *BMC Health Services Research*.

Canada

Making Way for Change: Transforming Home & Community Care for Ontarians

ONTARIO ASSOCIATION OF COMMUNITY CARE ACCESS CENTRES | Online – 23 October 2014 – The Association's white paper, which includes four key recommendations, points out that home and community care system in the province is currently guided by a complex, unaligned patchwork of legislation, regulation and provincial policies that has not undergone a comprehensive review in two decades of significant health care and other public policy shifts. A modernized statute and accompanying regulatory and policy changes would help embed a renewed home and community care sector as a key pillar of the health care system, with appropriate authority and accountability for achieving sector goals in support of health system transformation objectives. http://oaccac.com/Policy/White%20Paper/OACCAC-Whitepaper-FINAL.pdf

Of related interest:

ALBERTA | CBC News (Edmonton) – 20 October 2014 – 'Long-term care, supportive living and home care – how do they differ?' The levels of care offered to Alberta seniors can be confusing, especially as the government announces measures to move people out of hospital beds into more appropriate settings. Here's how Alberta Health Services defines the different types of care available. http://www.cbc.ca/news/canada/edmonton/long-term-care-supportive-living-and-home-care-how-do-they-differ-1.2806233

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.17.

Hospice faces donor revolt if it partners with the hospital

ONTARIO | Bay Today (North Bay) — 21 October 2014 — North Bay Regional Health Centre (NBRHC) President and CEO Paul Heinrich ... says that a formal request from the North East Local Health Integration Network has the hospital and the Nipissing Serenity Hospice conducting a joint business plan to evaluate the pros and cons of having the hospice in the hospital building. But the chairperson of the Nipissing Serenity Hospice, Mathilde Bazinet, is not sure the idea will be accepted by the hospice board members. Bazinet says three community groups have been very active in fundraising for the North Bay hospice. "The reaction couldn't be more negative," Bazinet adds. "Many donors are threatening to take back their money if the NBRHC is involved." The hospital wants us to pay \$205,000 dollars of rent per year. And then we would have to renovate the unit offered for the hospice. And we are responsible for the operating costs. The necessary funds must all be fundraised." The province will only give funding for nurses and personal support workers for patient care. http://www.baytoday.ca/content/news/details.asp?c=68060

U.S.A.

Life means death for thousands of Pennsylvania prisoners

PENNSYLVANIA | NBC News (Philadelphia) – 21 October 2014 – Because state law gives them no possibility of parole, nearly all of more than 5,300 inmates serving life terms will eventually die inside prison walls. "They have no choice but to age and die in place," said Julia Hall, a criminal justice professor and gerontologist at Drexel University. In the Laurel Highlands prison, seven rooms are the final stop for some of the state's sickest and oldest inmates. With breathing tubes and IVs, the ... inmates wait for their bodies to fail. When their vital signs slip and they struggle for breath, other inmates hold vigil so they won't die alone. Sometimes death is sudden. Other times, volunteers like Christian, a 32-year-old inmate from Philadelphia, watch as life slowly slips away. https://www.nbcphiladelphia.com/news/local/Life-Means-Death-for-Thousands-of-Pennsylvania-Prisoners-279936712.html

Of related interest:

ILLINOIS | The Chicago Sun-Times – 23 October 2014 – 'Illinois needs better way to deal with terminally ill inmates.' When America's prisons start looking like hospice care facilities for old and dying inmates, we're wasting a lot of money. Treating growing numbers of terminally ill inmates is so expensive that the federal government and some states are considering releasing many of these inmates in their final weeks of life if their families want to take them in. http://www.suntimes.com/opinions/30463534-474/illinois-needs-better-way-to-deal-with-terminally-ill-inmates.html#.VEqYJiLF YQ

N.B. The provision and delivery of end-of-life care in the prison system have been highlighted in Media Watch on a regular basis. A compilation of articles, reports, etc., on this public health issue noted in the weekly report in recent years is available online at the Palliative Care Community Network website: http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons.

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

Patient experience officers aim to improve communication

NORTH CAROLINA | The Charlotte Observer – 20 October 2014 – As chief patient experience officer for Carolinas HealthCare System, Connie Bonebrake is working to improve physician-patient communication. Carolinas HealthCare has twelve patient and family advisory councils that provide feedback for the system's Charlotte-area hospitals Some patient advisers have had "less than perfect experiences," but have chosen "productive ways to help us be better," Bonebrake said. "This is the kind of thing my position was created for. We know that

communication is important and that historically we [those in health care] have not necessarily been the best communicators." http://www.charlotteobserver.com/2014/10/18/5250844/patient-experience-officers-aim.html#.VET19SLF_YQ

Specialist Publications

'Defining patient experience' (p.15), in *Patient Experience Journal*.

Hospice vs. palliative care

Commissioners want more study on palliative care before deciding

NORTH CAROLINA | *The Sun-Journal* (New Bern) – 20 October 2014 – The Craven County Board of Commissioners will further study the pros and cons of county government expanding its direct health care offerings to include palliative care... With a small group of protesters calling for "no county hospice" greeting members as they arrived ... for their Monday meeting – and a number of hospice supporters at the meeting as well – there are clearly pros and cons to consider. Board Chairman Tom Mark appointed a study committee ... to meet directly with other palliative care providers and get additional information before deciding. Palliative care and hospice – either inpatient or outpatient hospice – are not the same thing, although some palliative care is part of hospice care, or end-of-life care. http://www.newbernsj.com/news/local/commissioners-want-more-study-on-palliative-care-before-deciding-1.389464

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- PEW RESEARCH CENTER | Online 22 October 2014 'Americans of all ages divided over doctor-assisted suicide laws.' Brittany Maynard, a 29-year-old woman with terminal brain cancer, has gone public with her plans to take her own life ... to make the case for more widespread laws allowing doctor-assisted suicide for terminally ill patients. A report issued by the Institute of Medicine (part of the National Academy of Sciences) last month called for an overhaul of end-of-life care nationwide, including, for example, a greater emphasis on advance care planning and Medicare funding for home health services. A chairman of the committee that conducted the study told The New York Times that "the current system is geared towards doing more, more, and that system by definition is not necessarily consistent with what patients want."2 A Pew Research Center survey conducted last year found that two-thirds of Americans say there are circumstances in which a patient should be allowed to die, as opposed to doctors and nurses always doing everything possible to save the life of a patient.3 But U.S. adults are more divided about laws that allow doctor-assisted suicide for terminally ill patients, with 47% in favor of such laws and 49% opposed. Views on doctor-assisted suicide are little changed since 2005. http://www.pewresearch.org/fact-tank/2014/10/22/americans-of-allages-divided-over-doctor-assisted-suicide-laws/
 - 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, National Academy of Sciences, Washington DC, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] http://www.iom.edu/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf

Cont.

- 'Panel urges overhauling health care at end of Life,' The New York Times, 17 September 2014. http://www.nytimes.com/2014/09/18/science/end-of-life-care-needs-sweeping-overhaul-panel-says.html? r=0
- Views on End-of-Life Medical Treatments,' Pew Research Center, Washington DC, November 2013. [Noted in Media Watch, 25 November 2013, #333 (p.2). http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/

International

End-of-life care in Australia

Call for rethink on end-of-life care as health costs climb

AUSTRALIA (Australian Capital Territory) | The Canberra Times - 22 October 2014 -Frontline health workers are calling for an overhaul of end-of-life care to reduce the number of people dying in hospitals and help rein in spiralling spending. Medicare Local, which represents GPs, nurses, pharmacists and other primary health and consumer groups, has made the suggestion in a submission to the territory budget, pointing to fast and unsustainable increases in health spending. In the Australian Capital Territory, 21% of hospital admissions in 2011-2012 were potentially preventable. People aged 65 to 75 were twice as likely to be admitted to hospital as the rest of the population, and people aged over 85 were five times more likely. These age groups also had more visits to GPs, used more medication and were in hospital longer. These costs to the health system were huge, the group said in its submission, urging a study of hospitalisation among older people to establish costs, reasons and how many visits were potentially avoidable. While 70% of people wanted to die at home, only 14% did so. Each year, more than \$2 billion was spent on older people who die in hospital. Most people died in acute care settings; many being "actively treated" to the moment of death, with futile treatments ... calling for more work on end-of-life care to avoid "overly medicalised" deaths.http://www.canberratimes.com.au/act-news/call-for-rethink-on-endoflife-care-as-health-costs-climb-20141022-119ut0.html

Specialist Publications

'Dying in Australian hospitals: Will a separate national clinical standard improve the delivery of quality care?' (p.8), in Australian Health Review.

'Use of advance directives by South Australians: Results from the Health Omnibus Survey Spring 2012' (p.12), in *Medical Journal of Australia*.

Of related interest:

AUSTRALIA | Australasian Science - Accessed 23 October 2-014 - 'Is evidence-based medicine in palliative care doing more harm than good?' Clinicians use evidence-based practices in most medical specialities to give their patients the best possible treatment. When it comes to palliative care, however, the literature is bombarded with articles about the challenges of obtaining quality evidence in this important aspect of medicine. Those challenges stem from a multitude of factors... http://www.australasianscience.com.au/article/issue-november-2014/evidence-based-medicine-palliative-care-doing-more-harm-good.html

Media Watch posted on Palliative Care Network-e Website

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

Elder care in England

Is this a good time to dilute care home rules?

U.K. (England) | The Guardian – 21 October 2014 - A Care Quality Commission ... report¹ was published last week on the day a dozen MPs met for twenty-five minutes in a [House of] Commons committee room to nod through new statutory regulations for care homes. These regulations, to be part of "fundamental standards" across health and social care, include a "duty of candour" on the part of care providers when things go wrong and a "fit and proper persons" test for directors of care organisations. Both measures are to apply immediately in the National Health Service, but from next year to all care providers. But curious – to some observers. alarming - changes are being made deep in the detail of the Health & Social Care Act 2008... In the name of "light-touch" regulation, existing rules governing care homes are being pruned and rationalised. Out goes a requirement homes must inform residents of complaints procedures; out goes a stipulation homes must offer a choice of food; and, out ... goes a requirement to plan for and have in place emergency procedures. http://www.theguardian.com/society/2014/oc t/21/dilute-care-home-rules-law-abuse

Case study included in Care Quality Commission report:

See 'Excellent care at Hope House Children's Hospice,' which serves Shropshire, Cheshire and north and mid-Wales (p.31).

Specialist Publications

'Choosing care homes as the least preferred place to die: A cross-national survey of public preferences in seven European countries' (p.9), in *BMC Palliative Care*.

'Position statement from the Japan Geriatrics Society 2012: End-of-life care for the elderly' (p.11), in *Geriatrics & Gerontology International*.

'Improving the organization of palliative care: Identification of barriers and facilitators in five European countries' (p.13), in *Implementation Science*.

'The State of Health Care & Adult Social Care in England, 2013-2014,' Care Quality Commission, 16 October 2014. http://www.cqc.org.uk/content/state-care-2013-14-infographic

Of related interest:

U.K. | The Daily Mail – 23 October 2014 – '340,000 elderly will be denied care in new cuts...' Councils have been told to provide home helps and other assistance only if people are unable to complete two or more essential daily tasks. If they are unable to do only one of the 10 appointed tasks they should receive no help from their council – meaning they would have to pay for care themselves or do without it. http://www.dailymail.co.uk/news/article-2805764/340-000-elderly-denied-care-new-cuts-Vital-help-restricted-need-assistance-two-tasks.html

Elder care in Ireland

Watchdog can't probe complaints about care facilities

IRELAND | *The Independent* (Dublin) – 20 October 2014 – The Health Information & Quality Authority (HIQA) says it does not have the legal powers to investigate "unsolicited" complaints it receives from health professionals and the relatives of residents. The authority received 355 such complaints about 213 nursing homes last year – over a third of the country's elder care facilities. However, deficiencies in legislation mean these cannot be individually probed. http://www.independent.ie/irish-news/news/watchdog-cant-probe-complaints-about-care-facilities-30676831.html

The return of the pauper's funeral to austerity Britain

U.K. | The Guardian – 20 October 2014 – Funeral poverty is an unexpectedly potent indicator of the combined impact of recession, austerity, low wages and the insecure job market. The insurance company Sun Life Direct says funeral poverty has risen by 125% since 2010 – a figure it calculates by assessing the shortfall between the cost of funerals and people's ability to pay. Around one in seven people struggle to pay funeral costs – with the average cost of a basic funeral around £3,590, according to the company's research. Funeral charities and crematorium staff report a rise in demand for the state-funded funeral, and note that while it was designed for those who died alone, increasingly it is being used to bury people whose families are unable to meet the cost of arranging a ceremony. https://www.theguardian.com/society/2014/oct/20/paupers-funeral-austerity-britain-soaring-costs-bury-loved-ones

 'Cost of Dying: 8th Annual Report 2014,' Sun Life Direct, October 2014. https://www.sunlifedirect.co.uk/blogs-and-features/can-you-afford-to-die -cost-of-dying-rises/

End-of-life care in England

"Do not resuscitate" patient controversy

U.K. (England) | BBC News – 20 October 2014 – Many of us will end up in hospital at the end of our lives, but would we want doctors to attempt to resuscitate or let us pass away peacefully if we suffer a heart attack or stop breathing? 'Do Not Resuscitate' orders are common in hospitals but a recent landmark judgement by the High Court is starting to have profound effects on patient care. Under the ruling doctors must ask patients and/or their relatives whether they want to be resuscitated. BBC Inside Out's Chris Jackson talks to doctors at the Royal Victoria Infirmary in Newcastle about their concerns over patient resuscitation. He also asks Dr. Claud Regnard, a consultant in palliative care, about the implications of the ruling and how it can be "traumatic" for patients and their relatives. http://www.bbc.com/news/uk-england-29631353

1. 'Legal duty over resuscitation orders,' BBC News, 17 June 2014. [Noted in Media Watch, 23 June 2014, #363 (p.6)] http://www.bbc.com/news/health-27886265

Noted in Media Watch, 13 October 2014, #379 (p.11):

BRITISH MEDICAL ASSOCIATION, (U.K.) RESUSCITATION COUNCIL & THE ROYAL COLLEGE OF NURSING | Online – Accessed 8 October 2014 – 'Decisions relating to cardio-pulmonary resuscitation.' This new edition ... identifies key ethical and legal principles that should inform all CPR decisions. https://www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf

Experimental drugs for patients could be available from March after Government backs Saatchi Bill

U.K. (England & Wales) | The Daily Telegraph – 19 October 2014 – Dying patients could be given access to untested medicines from early next year after the Government and doctors gave their backing to a bill proposed by Lord Saatchi. Jeremy Hunt, the Health Secretary, has now thrown his department's weight behind the Medical Innovation Bill, which will make it easier for doctors to try out new treatments on patients without the fear of being sued. The Bill – which has sharply divided the medical profession – received tentative backing from the General Medical Council, which earlier this

year come out firmly against any change in the law, and a leading cancer charity. http://www.telegraph.co.uk/health/saatchibill/11173161/Experimental-drugs-forpatients-could-be-available-from-Marchafter-Government-backs-Saatchi-Bill.html

Specialist Publications

"'Right to try" laws [in the U.S.]' (p.10), in Clinical Trials.

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

Medical record documentation and symptom management at the end of life in the neonatal intensive care unit

ADVANCES IN NEONATAL CARE | Online – 13 October 2014 – In neonates, the course of illness is often unpredictable and symptom assessment is difficult. This is even truer at the end of life. Time to death can take minutes to days, and ongoing management of the infant is needed during the time between discontinuation of life-sustaining treatment and death to ensure that the infant remains free of pain and suffering. The symptoms experienced by neonates as they die, as well as best ways to treat those symptoms, are understudied. Inadequate documentation in the medical record resulted in missing data that made it not possible to fully explore aspects of symptom management during the last 24 hours of life; however, some important results were found. http://journals.lww.com/advancesinneonatalcare/Abstract/publishahead/Medical Record Documentation and Symptom.99976.aspx

Of related interest:

ARCHIVES OF DISEASE IN CHILDHOOD | Online – Accessed 21 October 2014 – 'Care around an infant's death in the neonatal intensive care units.' The aim of this study was to explore ... supportive care in European neonatal intensive care units. This is a first attempt to benchmark this sensitive practice. http://adc.bmj.com/content/99/Suppl 2/A489.1.abstract

Noted in Media Watch, 13 October 2014, #379 (p.14):

JOURNAL OF PEDIATRIC & NEONATAL INDIVIDUALIZED MEDICINE, 2014;3(2):e030261.
'Changing the focus of care: From curative to palliative care.' The improvements in the obstetrical and neonatal diagnosis and therapies have resulted in an increase in the survival rate of infants previously considered as non-viable. Debate is focusing on professionals' behaviour about withdrawal or withholding of life sustaining treatment and administration of palliative care for newborns whose conditions are incompatible with a prolonged life.
http://www.jpnim.com/index.php/jpnim/article/viewFile/030261/189

Ethics and end-of-life care

Physicians' perspectives on ethically challenging situations: Early identification and action

AMERICAN JOURNAL OF BIOETHICS: EMPIRICAL BIOETHICS | Online – 13 October 2014 – Representing 30 specialties, 114 physicians responded [to an online survey]. The most frequently encountered situation was working with patients who lacked capacity for decision making. End-of-life treatment decisions and family adamancy were ranked as the most intense situations. Interactional risk factors such as different moral perspectives and poor communication were most prominent; patient and family risk factors were also described. Physicians identified early and frequent communication with seriously ill patients and their families as the primary protection against ethical conflict. Ethics skill-building, good teamwork, and creating an ethics-minded culture were featured as important preventive measures. Pressure from others to take morally uncomfortable action was cited as a source of moral stress. The pressure of limited time to address ethical issues was frequently mentioned. These could progress to ethical conflicts, which often compounded moral stress. A majority of physicians reported willingness to work with nurses on ethically difficult situations. http://www.tandfonline.com/doi/abs/10.1080/23294515.2014.972527#.VEZgiiLF YQ

Of related interest:

■ LAW TIMES (Ontario, Canada) | Online – 20 October 2014 – 'Lawyers worry about misuse of prior capable wishes by doctors.' There's growing frustration among patient advocates over the depth of misunderstanding in the medical system regarding the prior capable wishes of patients who now require others to make their decisions for them. Not only are substitute decision-makers unsure of how to handle these wishes, but the medical profession often ignores them or applies them without any input from the patient or the personal attorney and it sometimes ... completely out of context. http://www.lawtimesnews.com/201410204260/focus-on/focus-lawyers-worry-about-misuse-of-prior-capable-wishes-by-doctors

Dying in Australian hospitals: Will a separate national clinical standard improve the delivery of quality care?

AUSTRALIAN HEALTH REVIEW | Online – 19 October 2014 – More than 50% of Australian deaths occur in hospital. Despite this, hospitals often view themselves as poorly equipped to provide high quality care to people dying expected deaths, sometimes resulting in a gap between the actual and expected experiences of dying people. While home deaths are one outcome, the changing demographics of Australian society, coupled with the fact that for many people hospital is the preferred place of death, dictates a need for hospitals to consider how the care of dying people can be better and more reliably provided. This perspective highlights the opinion that a single standard is unlikely to address the hoped for improvement in the delivery of quality care. http://www.publish.csiro.au/view/journals/dsp journals pip abstract scholar1.cfm?nid=270&pip=

Care planning

"No decision about me without me" in the context of cancer multidisciplinary team meetings: A qualitative interview study

BMC HEALTH SERVICES RESEARCH | Online – 24 October 2014 – Patients do not attend MDT [multidisciplinary team] meetings, but recommendations for treatments made in the meetings directly influence the decision-making process between patients and their responsible clinician. No research to-date has considered patient perspectives (or understanding) regarding MDTs or MDT meetings, though research has shown that failure to consider patient-based information can lead to recommendations that are inappropriate or unacceptable, and can consequently delay treatment. Patients (i.e., study participants) had limited opportunities to input to or influence the decision-making process in MDT meetings. Key explanatory factors included that patients were given limited and inconsistent information about MDTs and MDT meetings, and that MDT members had variable definitions of patient-centredness in the context of MDTs and MDT meetings. Reassurance emerged as a "benefit" of informing patients about MDTs and MDT meetings. https://www.biomedcentral.com/content/pdf/s12913-014-0488-2.pdf

Of related interest:

■ BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 October 2014 – 'How to communicate with patients about future illness progression and end of life: A systematic review.'

Practices vary in how strongly [articles reviewed] encourage patients to engage in talk about matters such as illness progression and dying. Fishing questions and indirect talk make it particularly easy to avoid engaging – this may be appropriate in some circumstances. Hypothetical questions are more effective in encouraging on-topic talk, as is linking questions to patients' cues. Shifting towards more "optimistic" aspects helps maintain hope but closes off further talk about difficulties: practitioners may want to delay doing so. There are substantial gaps in evidence. http://spcare.bmj.com/content/early/2014/10/24/bmjspcare-2014-000649.abstract

- JAMA INTERNAL MEDICINE | Online 20 October 2014 'Communication about serious illness care goals: A review and synthesis of best practices.' Best practices in discussing goals of care include: sharing prognostic information, eliciting decision-making preferences, understanding fears and goals, exploring views on trade-offs and impaired function, and wishes for family involvement. Several interventions hold promise in systematizing conversations with patients: better education of physicians; systems to identify and trigger early discussions for appropriate patients; patient and family education; structured formats to guide discussions; dedicated, structured sections in the electronic health record for recording information; and continuous measurement. http://archinte.jamanetwork.com/article.aspx?articleid=1916912
- MEDICAL JOURNAL OF AUSTRALIA, 2014;201(8):452-455. 'Goals of care: A clinical framework for limitation of medical treatment.' A novel clinical framework called "goals of care" (GOC) has been designed as a replacement for not-for-resuscitation orders. The aim is to improve decision making and documentation relating to limitations of medical treatment. Clinicians assign a patient's situation to one of three phases of care curative or restorative, palliative, or terminal according to an assessment of likely treatment outcomes. This applies to all admitted patients, and the default position is the curative or restorative phase. https://www.mja.com.au/journal/2014/201/8/goals-care-clinical-framework-limitation-medical-treatment
- MEDSCAPE | Online 22 October 2014 ""Co-rounding" cuts inpatient oncology stays, readmissions.' Good things happen when medical oncologists and palliative care specialists are equally responsible for cancer care on a hospital's inpatient oncology unit, according to results from a novel study. This pioneering collaborative model, dubbed "co-rounding," means that a physician from each specialty is present all day on the unit, as opposed to the usual model in which palliative care is consultative and a specialist stops by the floor. http://www.medscape.com/viewarticle/833646
- PSYCHO-ONCOLOGY | Online 24 October 2014 ""You can't say, 'what about me?' I'm not the one with cancer": Information and support needs of relatives.' Participants [in this study with relatives and partners] did not always want to know everything about the patient's illness, suggesting the importance of tailoring information to individual needs. Offering a range of different kinds of support directly to relatives may improve patient care and emotional well-being. http://onlinelibrary.wiley.com/doi/10.1002/pon.3716/abstract

Choosing care homes as the least preferred place to die: A crossnational survey of public preferences in seven European countries

BMC PALLIATIVE CARE | Online – 23 October 2014 – Care homes are increasingly becoming places where people spend the final stages of their lives and eventually die. This trend is expected to continue due to population ageing, yet little is known about public preferences regarding this setting. As part of a larger study examining preferences and priorities for end of life care, the authors investigated the extent to which care homes are chosen as the least preferred place of death, and the factors associated with this negative preference. Their results suggest it might be difficult to promote care homes as a good place to die. This is an urgent research area in order to meet needs and preferences of a growing number of older people with chronic, debilitating conditions across Europe. http://www.biomedcentral.com/content/pdf/1472-684X-13-48.pdf

Of related interest:

JOURNAL OF GERONTOLOGICAL NURSING, 2014;40(10);10-14. 'Evaluating the impact of palliative or hospice care provided in nursing homes.' The authors review the existing evidence relevant to nursing homes to provide practitioners with a greater understanding of the impact of palliative and hospice care on clinical care outcomes (e.g., pain, symptom management), processes of care outcomes (e.g., hospitalizations, cost of care), and family member or health care proxy perceptions of care. http://www.healio.com/nursing/journals/jgn/2014-10-40-10/%7B80a97d0e-ad57-438e-b7a5-8687bd5b21a2%7D/evaluating-the-impact-of-palliative-or-hospice-care-provided-in-nursing-homes

What do bereaved parents want from professionals after the sudden death of their child: A systematic review of the literature

BMC PEDIATRICS | Online – 13 October 2014 – The review includes data from 52 papers, concerning 4,000 bereaved parents. After a child has died, parents wish to be able to say goodbye to them at the hospital or Emergency Department, they would like time and privacy to see and hold their child; parents may bitterly regret not being able to do so. Parents need to know the full details about their child's death and may feel that they are being deliberately evaded when not given this information. Parents often struggle to obtain and understand the autopsy results even in the cases where they consented for the procedure. Parents would like follow-up appointments from health care professionals after the death; this is to enable them to obtain further information as they may have been too distraught at the time of the death to ask appropriate questions or comprehend the answers. Parents also value the emotional support provided by continuing contact with health-care professionals. http://www.biomedcentral.com/content/pdf/1471-2431-14-269.pdf

Noted in Media Watch, 20 October 2014, #380 (p.12):

• OMEGA – JOURNAL OF DEATH & DYING, 2014;69(4):421-435. 'Pediatric bereavement services: A survey of practices at children's hospitals.' This study was designed to identify types of bereavement support offered to parents whose child died at a pediatric hospital, to ascertain who provides support and to see how those services are institutionally organized and funded. The investigation gathered data using an online, custom-designed survey completed by bereavement providers at 122 of the 188 pediatric hospitals invited to participate... http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,5,6:journal,1,274;linkingpublicationresults,1:300329,1

"Right to try" laws

CLINICAL TRIALS, 2014;11(5):519-520. Recently, the States of Colorado and Louisiana have approved legislation that gives patients suffering from life-threatening illnesses the right to have access to experimental drugs that have passed phase I testing, and other states such as Arizona and Missouri may soon follow suit. These bills seek to allow access to experimental drugs to patients who have exhausted all available treatment options. The bill does not require the manufacturer to make a drug available to an eligible patient, but it does allow those manufacturers who elect to take advantage of the law to charge the patient for the costs of the drug, and it does not mandate coverage by health insurers. In short, it allows drug manufacturers to market their drugs prior to the efficacy testing needed for U.S. Food & Drug Administration [FDA] approval. A similar U.S. federal bill was developed nearly a decade ago ... 'Access, Compassion, Care & Ethics for Seriously III Patients Act.' At the time, the Society [for Clinical Trials] prepared an extended Position Paper opposing this legislation, describing the history of clinical trials and the reasons why controlled trials are essential to ensure that marketed drugs are safe and effective, and laying out the likely adverse consequences for the public health of any change in the law that would remove efficacy testing of drugs from the jurisdiction of the FDA. That bill never made it through the congressional committee system and as a result never came up for a vote. By contrast, 'Right to try' legislation has already been approved in Colorado and Louisiana, and it sets up a potential conflict between state and federal laws on this issue. http://ctj.sagepub.com/content/11/5/519.full

 Position paper: The Society for Clinical Trials opposes U.S. legislation to permit marketing of unproven medical therapies for seriously ill patients,' *Clinical Trials*, 2006;3(2):154-157. http://ctj.sagepub.com/content/3/2/154.full.pdf+html?ijkey=ba270f74c3ddd04bf31559917cf42b b68062cb52&keytype2=tf ipsecsha Noted in Media Watch, 6 October 2014, #378 (p.11):

JAMA INTERNAL MEDICINE | Online – 29 September 2014 – 'The strange allure of state 'right-to-try' laws.' State "right-to-try" laws that purport to allow patients to be treated with unapproved drugs or devices seem likely to be futile. In May 2014, the governor of Colorado signed into law a so-called right-to-try bill; the intent of the law is to allow terminally ill patients to receive treatment outside of clinical trials with drugs and medical devices that the FDA has not approved for marketing. http://archinte.jamanetwork.com/article.aspx?articleid=1910562

Knowledge sharing and innovative work behaviour in healthcare: A micro-level investigation of direct and indirect effects

CREATIVITY & INNOVATION MANAGE-MENT | Online - 17 October 2014 - This study ... provides new insights into how employees' knowledge sharing affects their own innovative work behaviours (IWBs). It posited three mechanisms linking an individual's knowledge sharing behaviours to his or her own IWBs: 1) a direct effect whereby the act of sharing elicits a recombination and translation of knowledge that facilitates innovation; 2) an indirect effect whereby knowledge sharing creates social conditions (i.e., reciprocation with new knowledge) for innovation; and, 3) a distal effect whereby the antecedents of knowledge sharing also promote innovation. There results provide original evidence that employees who share knowledge also engage more in creating, promoting and implementing innovations. This

study reveals a direct, unmediated link between knowledge sharing behaviours and IWBs. The authors' evidence suggests that it is the act of knowledge recombination and translation embedded in knowledge sharing that exerts the most positive effect on IWBs. <a href="http://onlinelibrary.wiley.com/doi/10.1111/caim.12084/abstract;jsessionid=5A5E4FA0BA019BB55D7F5FEA31E0DF0F.f04t01?deniedAccessCustomisedMes-sage=&userlsAuthenticated=false

The authors' hypothesis

...was tested on 155 employees in four palliative care organizations.

Position statement from the Japan Geriatrics Society 2012: End-of-life care for the elderly

GERIATRICS & GERONTOLOGY INTER-NATIONAL, 2014;14(4):735-739. The Japan Geriatrics Society published a revised version of its position statement regarding the end-of-life care for elderly patients, based on the overall consensus by the members of the ethics committee in 2012. This revision is intended to catch up with current changes of views on the end-of-life care for older people over the past decade. There are many suggestive items regarding the matter in this statement, and the authors believe it will be of specific guidance for those who are caring for older people in their final stage of life in the super-aged society. The authors believe that this "position statement" can offer guidance in an ethical respect for those

who are or will be engaged in end-of-life care for older people. They also hope that the release of the current statement provides an avenue for broader discussion in a society with an increasing aged population. http://onlinelibrary.wiley.com/enhanced/doi/10.1111/ggi.12322/

Extract from Geriatrics & Gerontology International article

...the [position] statement can be useful in many other countries, where aging of the population is not yet an urgent concern, but will be so in the future.

Noted in Media Watch, 1 September 2014, #373 (p.10):

JOURNAL OF THE JAPAN HOSPITAL ASSOCIATION, 2014;(33):35-43. 'Reduction in the number of hospital beds in a super-aging society: An upsurge in isolation deaths.' It is essential to provide hospital beds to elderly patients with the imminent risk of dying to prevent them from isolation deaths because... http://europepmc.org/abstract/med/25145114

Noted in Media Watch, 20 January 2014, #341 (p.12):

■ JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online – 11 January 2014 – 'Regional medical professionals' confidence in providing palliative care, associated difficulties and availability of specialized palliative care services in Japan.' Confidence in providing palliative care was low and difficulties frequent for all types of medical professionals assessed. http://jico.oxfordjournals.org/content/early/2014/01/08/jjco.hyt204.abstract

Noted in Media Watch, 26 November 2012, #281 (p.9):

■ JAPANESE JOURNAL OF CLINICAL ONCOLOGY | Online — 19 November 2012 — 'Past, present, and future of palliative care in Japan.' Palliative care is steadily growing with a trend away from palliative care units toward palliative care teams and care in the home. http://jico.oxfordjournals.org/content/early/2012/11/18/jico.hys188.abstract

Understanding patients' and doctors' attitudes about shared decision making for advance care planning

HEALTH EXPECTATIONS | Online – 22 October 2014 – Although patients described participation in decision making, many deferred the final decision to their doctors. Doctors indicated a preference for shared decision making, but expressed barriers including perceived lack of patient understanding and lack of patient empowerment. With regard to end-of-life discussions, patients were generally open to having these discussions with their doctors, although their openness sometimes depended on the circumstance (i.e., end-of-life discussions may be more acceptable to patients for whom the chance of dying is high). Doctors reported engaging in end-of-life treatment decisions with their patients, although expressed the need for conversations to take place earlier, in advance of acute illness, and identified a lack of prognostic estimates as one barrier to engaging in this discussion. https://onlinelibrary.wiley.com/doi/10.1111/hex.12285/abstract

N.B. Several articles on shared decision making noted in past issues of Media Watch are listed in the 25 August 2014 issue of the weekly report (#372, pp.14-15).

Of related interest:

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online 21 October 2014 'Advance care planning in people with early cognitive impairment.' A large proportion of patients [i.e., study participants] with early cognitive impairment decline advance c are planning discussions and the reasons are influenced by personal values, coping behaviours and socio-cultural norms. http://spcare.bmj.com/content/early/2014/10/21/bmjspcare-2014-000648.abstract
- MEDICAL JOURNAL OF AUSTRALIA, 2014;201(8):467-469. 'Use of advance directives by South Australians: Results from the Health Omnibus Survey Spring 2012.' Completion rates of advance directives (ADs) among South Australians remain low, with financial instruments more likely to be completed than health care and lifestyle instruments. The odds of not completing ADs were associated with age and socioeconomic characteristics. https://www.mja.com.au/journal/2014/201/8/use-advance-directives-south-australians-results-health-omnibus-survey-spring

pg. 12

Improving the organization of palliative care: Identification of barriers and facilitators in five European countries

IMPLEMENTATION SCIENCE | Online - 13 October 2014 - This study identified barriers and facilitators to organizational change in palliative care. Some of these ... were experienced by professionals in almost all countries (i.e., England, Germany, Italy, Norway and The Netherlands) and are therefore prerequisites to change. In order to promote successful implementation of change, it is important to tailor an organizational improvement to the needs of individuals and organizations. Barriers and facilitators were inductively grouped into 16 categories and arranged into five themes: innovation, individual professional level, group dynamics, organizational context and local political-economic context. Although the barriers and facilitators identified differed in scope, context, strength and provenance, they were shared by professionals from different European countries. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4203898/

Too sick to move: Distant "crisis" care in transnational families

INTERNATIONAL REVIEW OF SOCIOLOGY | Online – 13 October 2014 – This paper examines the crisis of acute and chronic illness, death, and dying in transnational families. These are the stages in the family life-course when physical co-presence is required to deliver hands-on care and intimate emotional support for the sick family member. It is a time when distant kin feel they need "to be there," including for their own sense of well-being. This period of "crisis" (in the anthropological sense) makes visible all of the impediments to transnational family caregiving that often remain hidden during those periods when "routine" forms of distant care are adequate. Of particular relevance are the macro-level factors generated by national borders and the policies that define them, including those that govern employment, travel, visa, health, and aged care provisions. It is in these family life phases of crisis that nation-state structures can work to constrain individual agency and rights, making compellingly evident the growing need for transnational structures and policy. http://www.tandfonline.com/doi/abs/10.1080/03906701.2014.954328

Noted in Media Watch, 18 August 2014, #371 (p.11):

■ JOURNAL OF PALLIATIVE MEDICINE | Online – 15 August 2014 – 'Transnationals' experience of dying in their adopted country: A systematic review.' Social and emotional challenges of migration and integration include managing memories and perceptions of country of birth, leaving loved relatives behind, and the challenges of maintaining traditions, such as cultural food and practices. For many migrants, the strong connection with their birth country is never completely severed, which may become pertinent at particular events and stages in life with inherent emotional impact. http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0044

The functional role of music in communicating death through/in YouTube videos

JOURNAL OF EDUCATION CULTURE & SOCIETY, 2014;1:206-217. Even in modern societies, death remains a taboo topic, which shows in people's reluctance to engage in conversations that deal with that subject. After the emergence of thanatology as the science of death in the 1950s, many theorists and researchers suggested different explanations surrounding these matters, with some of them subscribing to the view that people subconsciously believe in their immortality and they do not want to consider death as part of their lives. In the last two decades, the character of debate about death has gone beyond the personal and involved media and communication technologies. Currently, death is communicated by way of various media platforms such as films, television, radio and online videos. However, this communication of death does not negate the confrontation of death as a taboo subject. Communication of death via video platforms has many dimensions, with music being the crucial one. Recent research has showed that music has specific characteristics that prove it able to communicate feelings and express inner emotions, but can also induce and alter them. file:///C:/Users/Barry/Downloads/CEEOL%20Article.PDF

Planning for the move from children's to adult palliative care

MEDICAL XPRESS | Online - 21 October 2014 - The differences between children's and adult palliative care services are too wide for young people with life-limiting conditions to negotiate, according to research by Bangor University. The researchers call for adult palliative care services to extend their scope to better meet the needs of young people with life-limiting conditions and their families. Planning for the move from children's to adult palliative care was often not focussed on the young person and what they wanted or needed. Many young people did not have a "key worker" or someone to support them in organising their transition so it was easy for young people to get lost and fall through the gaps. Important things such as the young person's views on their fluctuating pain and symptom management and changes in the way that the young person liked or needed to eat and drink were often not covered by current transition plans. Young people and parents [i.e., study participants] also highlighted the differences between children's and adult palliative care services and how this affected them. Young people with life-limiting conditions were used to "parallel planning" whereby children's palliative care services provided holistic support from diagnosis onwards for young people and their families to enjoy life as well as planning ahead for end of life care when needed. Young people said that holistic palliative care services for the entire family that had been of great benefit during childhood frequently ceased on transfer to adult services. Adult palliative care services, on the other hand, were more geared to meet the needs of primarily older people with conditions such as cancer or heart failure towards or at the end of life. http://medicalxpress.com/news/2014-10-children-adult-palliative.html

Noted in Media Watch, 17 February 2014, #345 (p.12):

NURSING CHILDREN & YOUNG PEOPLE, 2014;26(1):8-9. 'The challenges faced when leaving a children's hospice.' The move into adult services can leave young people with life-shortening conditions ... facing an uncertain future as they leave the comfort of children's services behind. http://rcnpublishing.com/doi/pdfplus/10.7748/ncyp2014.02.26.1.8.s9

N.B. Footnoted in this issue of Media Watch is a representative sample of articles noted in past issues of the weekly report on the transition to adult services for young people living with a terminal illness.

End-of-life care in the U.S.

National nursing organizations collaborate to transform care for patients with serious illness

NEWS MEDICAL | Online – 20 October 2014 – Three national nursing organizations announced a collaborative effort to transform the care and culture of serious illness in the U.S. Together, the Hospice & Palliative Nurses Association, the Hospice & Palliative Nurses Foundation, and the Hospice & Palliative Credentialing Center launched a \$5 million campaign aimed at increasing the number of certified hospice and palliative nurses, advancing research into best practices of hospice and palliative care, elevating palliative nursing leadership at the local and national levels, and enhancing nursing competence through certification. The announcement of the campaign comes on the heels of the Institute of Medicine's 500-page report, 'Dying in America.' The 21-member Institute committee that authored the report found, despite efforts to improve access to hospice and palliative care over the past decade, there are still major gaps, including a shortage of caregivers proficient in palliative care. http://www.news-medical.net/news/20141020/National-nursing-organizations-collaborate-to-transform-care-for-patients-with-serious-illness.aspx

 '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)] http://www.iom.edu/~/media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf

Cont.

Noted in Media Watch, 20 October 2013, #380 (p.13):

NURSING STANDARD, 2014;29(7):8. 'Fears raised over staff shortage in palliative care.'
 The quality of care for dying people could be put at risk because of a looming recruitment crisis in palliative care nursing... http://rcnpublishing.com/doi/abs/10.7748/ns.29.7.8.s4

14-year synthesis of existing literature

Defining patient experience

PATIENT EXPERIENCE JOURNAL, 2014;1(1). The authors' findings identified several concepts and recommendations to consider with regard to the definition of patient experience. First, the patient experience reflects occurrences and events that happen independently and collectively across the continuum of care. Also, it is important to move beyond results from surveys, for example those that specifically capture concepts such as "patient satisfaction," because patient experience is more than satisfaction alone. Embedded within patient experience is a focus on individualized care and tailoring of services to meet patient needs and engage them as partners in their care. Next, the patient experience is strongly tied to patients' expectations and whether they were positively realized (beyond clinical outcomes or health status). Finally, the patient experience is integrally tied to the principles and practice of patient- and family- centered care. As patient experience continues to emerge as an important focus area across healthcare globally, the need for a standard consistent definition becomes even more evident, making it critical to ensure patient experience remains a viable, respected, and highly embraced part of the healthcare conversation. http://pxjournal.org/journal/vol1/iss1/3/

Media Watch: Editorial Practice

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

Distribution

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

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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.

Worth Repeating

Euthanasia as a caregiving fantasy in the era of the new longevity

AGE, CULTURE, HUMANITIES, 2014;1(Spring). Michael Haneke's *Amour* received an exceptional degree of adulation for a film in which a husband smothers his frail, helpless wife. It won the Palme d'Or at Cannes 2012. The American Academy nominated it in five categories, including best actress for Emmanuelle Riva, the murderee, and Best Foreign Language Film (which it won). Although some reviews hinted that Jean-Louis Trintignant's perfect caregiving as the husband, Georges, would go sour, most avoided critiquing the shocking ending. In fact, without giving it away, they praised it. Calling all the (unspecified) violence in Amour "crucial," The New York Times' Dargis described Haneke's worldview as "liberatingly unsentimental." A Boston Globe critic praised the film's "hard, hushed sanctity" (Ty Burr). The husband, Georges, "copes in his own mad, heroic way," Peter Conrad gushed in The Guardian. Haneke even won a prize from Vienna's Society for Geriatrics & Gerontology (Gerontology Prize). That a strange film, seeming to explain euthanasia, has been highly acclaimed while remaining almost unexamined ethically is worrying. If there had already been other major feature films about end-of-life care in late life, Amour might be ignorable. If our society were not implicitly ageist in many ways - a case in point is the American President's agreement to slash Social Security's Cost-of-Living Adjustment despite the fact that most Americans favor leaving it alone - we might, again, let it slide. http://ageculturehumanities.org/WP/euthanasia-as-acaregiving-fantasy-in-the-era-of-the-new-longevity/

As a general rule,

Media Watch does not report on publication/release of new "titles" (i.e., books, films, etc.). The Age, Culture, Humanities article, however, is an exception to the rule due primarily to the author's unique point of view. To quote the author: "...the ethical omission make Amour worth discussing and teaching - as a literaryvisual document whose signature event ramifies into nursing, film and theater, disability and age studies, psychoanalysis, philosophy, law, and social policy, and our hearts and lives." BRA

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Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://hospicecare.com/about-iahpc/newsletter/2014/10/media-watch/

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

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

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

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: http://aphn.org/category/media-watch/

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/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

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: http://ahpca.ca/ (Scroll down to 'Media Watch')

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): http://hpcconnection.ca/general-resources/in-the-news/

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

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