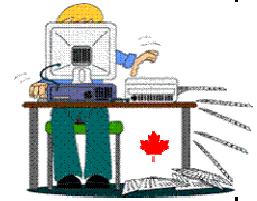


Media Watch...

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

Communities' role in their own health and social care: Scroll down to **Specialist Publications** and 'The impact of a new public health approach to end-of-life care: A systematic review' (p.17), in *Palliative Medicine*.

Canada

British Columbia Supreme Court grants temporary injunction to stop disabled baby from being taken off life support

BRITISH COLUMBIA (B.C.) | *The National Post* – 12 August 2015 – The parents of a severely disabled infant are waging a court battle against her caregivers in a bid to prevent the baby from being taken off life support. Five-month-old Mary Jane Pierce, who suffers multiple serious health problems, was due to be moved from B.C. Children's Hospital to Canuck Place ... where she would have been taken off a ventilator with the intent to let her die a natural death. However, in a last-minute decision by a B.C. Supreme Court judge, parents Justin Pierce and Michelle Arnold won a temporary injunction to stop the transfer and to keep the infant on a ventilator. The Chilliwack couple, who do not have custody of their child, argue that they did not consent to allow their baby to be taken off life support. However, the baby's guardians, the Fraser Valley Aboriginal Children & Family Services Society, contend that taking the child off life support is in her best interest to end her pain and suffering. Mary Jane was born premature at 25 weeks on 5 April. She has cerebral palsy and constant seizures, and has suffered multiple complications from meningitis. Despite being told that his daughter has little or no brain function, Pierce has hopes for the little girl's future after seeing her respond to stimuli. <http://news.nationalpost.com/news/canada/b-c-supreme-court-grants-temporary-injunction-to-stop-disabled-baby-from-being-taken-off-life-support>

Noted in Media Watch, 24 November 2014, #385 (p.3):

- ALBERTA | *The National Post* – 16 November 2014 – 'Taking Edmonton baby off life support is "kindest" option, judge rules after mother fights to keep her alive.' A baby born in Edmonton earlier this year [severely disabled by a deadly genetic defect] touched off the latest in a string of emotional end-of-life court battles, dying after a judge said removing her from life support was the "kindest" option available... The issue of who has the final say on life-and-death medical treatment remains legally hazy in most provinces, despite numerous court clashes. <http://news.nationalpost.com/2014/11/16/taking-edmonton-baby-off-life-support-is-kindest-option-judge-rules-after-mother-fights-to-keep-her-alive/>

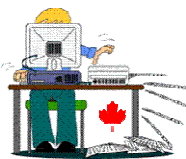
Elder care in Manitoba

Home care must be reinvented

MANITOBA | *The Winnipeg Free Press* – 12 August 2015 – The home care system in Manitoba is broken. Recently, provincial court Judge Michel Chartier pointed out communication and procedural deficits in the home care system.¹ Now, auditor general Norm Picard has identified a plethora of problems at many levels.² They include inconsistent and unreliable services, scheduling challenges, inefficient work schedules, incomplete client assessments and frequently cancelled visits due to staff shortages, requiring clients to have unrealistic backup plans on short notice. Staff are being told to do more in less time. Tasks are not being completed to anyone's satisfaction. Staff morale is low, and there are contract issues. There is an assembly-line mentality and not a very efficient one at that. It is not uncommon for a client to be seen by up to six different staff members in a two-day period. Home care is supposed to help people avoid or delay the need for costly stays in personal care homes or hospitals. Now it has become a broken link, a weak link at best. While the impact is economic, it is also personal, social and political. This is bound to get worse. The Department of Health, Healthy Living & Seniors has no plan in place to cope with the challenges the approaching silver tsunami will create for home care. <http://www.winnipegfreepress.com/opinion/analysis/home-care-must-be-reinvented-321522031.html>

1. 'Inquest into man's care-home death finds need for behavioural units,' *The Winnipeg Free Press*, 29 May 2015. <http://www.winnipegfreepress.com/local/Fatal-encounter--305422731.html>
2. 'Manitoba Home Care Program,' Office of the Auditor General Manitoba, July 2015. The audit examined Southern Health-Santé Sud and the Winnipeg Regional Health Authority that serve 75% of all Manitoba home care clients. [Noted in Media Watch, 10 August 2015, #422 (p.1)] <http://www.oag.mb.ca/wp-content/uploads/2015/08/Manitoba-Home-Care-Program-Report-Web-Version.pdf>

N.B. Palliative care services were not included in the auditor general's report: See 'More palliative care services needed in Manitoba, some help on way,' CBC Radio News, 23 April 2015 [Noted in Media Watch, 27 April 2015, #407 (p.1)].



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>

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.21.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | CBC News – 14 August 2015 – **‘Ontario forms expert panel on assisted dying.’** The Ontario government is setting up an advisory group to study physician-assisted dying, leading 11 provinces and territories in examining the controversial subject. The panel is similar to the one established by the federal government to inform its end-of-life legislation. The panels are a response to a Supreme Court decision in February that struck down the federal law prohibiting physician-assisted dying. The federal, provincial and territorial governments will need to craft laws around the court ruling by February 2016, when the ruling takes effect. Ontario and the participating provinces and territories say the primary responsibility to provide health care resides with them, and the panel will craft their response to the court ruling. The panel will provide advice on development of policies, practices and safeguards for provinces and territories to consider when physician-assisted dying is legal within their respective jurisdictions. <http://www.cbc.ca/news/canada/toronto/ontario-forms-expert-panel-on-assisted-dying-1.3191186>

Consultation on Legislative Options for Assisted Dying

The External Panel on Options for a Legislative Response to *Carter v. Canada* is adjusting its schedule of activities. The Panel will suspend direct consultations during the [federal] election... These will resume following the election 19 October 2015. It is the Panel's intention to continue a passive approach to consultation during the election period. This means the web site will continue to receive submissions and the on-line consultation tool will be available. The Panel will not respond to any materials or submissions received. <http://ep-ce.ca/en/home/>

Specialist Publications

‘The dilemma of positive rights: Access to health care and the Canadian Charter of Rights & Freedoms’ (p.20), in *Journal of Canadian Studies*.

‘Rethinking nonmaleficence – harm, the media and the advocate’s obligation’ (p.20), in *University of Toronto Medical Journal*.

N.B. Ontario government online survey: <https://www.ontario.ca/page/doctor-assisted-dying-and-end-life-decisions-consultation>

- PRINCE EDWARD ISLAND (PEI) | *The Globe & Mail* – 13 August 2015 – **‘Palliative care is improving, but Prince Edward Island must embrace wishes of the dying.’** More than 17% of the Island’s 140,000 people are over 65, compared to just over 15% for the country as a whole. In five years, the provincial figure will be 20%; in 25 years, it will be 30. Those figures in a largely rural population are a challenge for Mireille Lecours, palliative-care medical consultant for the province. She has made great strides in improving palliative care by supporting dying patients at home, in community-care facilities, as inpatients in palliative-care units, and especially in long-term-care facilities. Both the smallest and the most traditional of provinces, PEI has been rightly criticized for its refusal to offer abortion services on the Island and now is showing a similar reluctance to support patient choice in dying, despite the Supreme Court of Canada’s ruling last February legalizing physician-assisted death for competent adults with intractable physical or psychological suffering. Lecours hasn’t been invited to any provincial meetings to discuss the issue, even though the Supreme Court’s deadline to enact new federal legislation and provincial regulations is six months away. An extension of the deadline “would be the intelligent thing,” she says, because “we aren’t ready.” Pointing out both palliative care and home care are “extremely spotty” across the country, she argues every Canadian should have access to quality palliative care before they are offered physician-assisted death. <http://www.theglobeandmail.com/life/health-and-fitness/health/palliative-care-is-improving-but-pei-must-embrace-wishes-of-the-dying/article25958079/>

U.S.A.

A grief so deep it won't die

THE NEW YORK TIMES | Online – 14 August 2015 – The death of someone beloved often brings deep sadness. Usually, however, the intense grief of early mourning begins to ebb as months pass, and people alternate between continuing sorrow and a growing ability to rediscover life's pleasures. What distinguished Ms. [Anne] Schomaker's suffering was its sheer duration. She had been mired in grief for nine years when she saw an announcement from Columbia University, where researchers who had developed a treatment for "complicated grief" were seeking participants in a study. Maybe this new approach could help, Ms. Schomaker thought. Complicated or prolonged grief can assail anyone, but it is a particular problem for older adults, because they suffer so many losses – spouses, parents, siblings, friends. "It comes with bereavement," said Dr. Katherine Shear, the psychiatrist who led the Columbia University study. "And the prevalence of important losses is so much greater in people over 65." In a review¹ ... earlier this year, Dr. Shear listed several symptoms characteristic of complicated grief: intense longing or yearning, preoccupied thoughts and memories and an inability to accept the loss and to imagine a future without the person who died. http://www.nytimes.com/2015/08/18/health/complicated-grief-so-deep-it-wont-die.html?ref=health&_r=0

Noted in Media Watch, 23 February 2015, #398 (p.3):

- *THE NEW YORK TIMES* | Online – 16 February 2015 – '**When grief won't relent.**' Grief is a normal human reaction, not a disease, and there is no one right way to get through it. Most often, within six months of a death, survivors adjust and are more or less able to resume usual activities, experience joy, and remember their loved ones without intense pain. But sometimes, even when the loss is neither sudden nor unexpected survivors close to the deceased can experience extremely disruptive grief reactions that persist far longer. In a recently published report Dr. Katherine Shear presents a composite portrait of what is known as complicated grief.¹ http://well.blogs.nytimes.com/2015/02/16/when-grief-wont-relent/?ref=health&_r=0

1. 'Complicated grief,' *The New England Journal of Medicine*, 2015;372(2):153-160. Psychotherapy directed at the loss and at restoring activities and effective functioning is recommended. <http://www.nejm.org/doi/pdf/10.1056/NEJMcp1315618>

Media Watch: Back Issues



The screenshot shows the IPCRC.NET website. The header includes the logo and navigation links: Home, About IPM, OIA, NCI, Partners, Contact, Acknowledgements. Below the header, there is a section for 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' and 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE'. A featured article is titled 'MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care'. A sidebar on the right lists 'Media Watch Archives' with a list of years and months.

Media Watch Archives

- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

<http://www.ipcrc.net/archive-global-palliative-care-news.php>

Social workers want to talk religion – but they don't

UTAH | *Desert News* (Salt Lake City) – 14 August 2015 – Most social workers say they don't discuss religion or spirituality with their clients, even though they think it could be beneficial in treatment. And while some think it's a shame to cut religion out of the mix, others say it's a good thing. More than 60% of social workers surveyed in a recent study reported feeling they could competently incorporate a client's beliefs in treatment.¹ "I was really surprised to see that they were so confident in their ability to talk about this area of clients' lives, being able to integrate the clients' beliefs into clinical practice," said Baylor University professor Holly Oxhandler, co-author of a study of 442 social workers... Only 13% said they had taken a course on the role of a client's religion or spirituality in treatment, the study found. But Oxhandler said she has encountered many clients whose religious beliefs help them cope with

their symptoms and wanted to look at why more social workers don't consider this aspect of clients' lives. Integrating religion doesn't mean practitioners should impose their own values on clients, she added. <http://www.deseretnews.com/article/865634587/Social-workers-want-to-talk-religion-2-but-they-don7t.html>

Specialist Publications

'The serendipitous survey: A look at primary and specialist palliative social work practice, preparation, and competence' (p.16), in *Journal of Palliative Medicine*.

'Doctors discussing religion and spirituality: A systematic literature review' (p.18), in *Palliative Medicine*.

1. 'The integration of clients' religion and spirituality in social work practice: A national survey,' *Social Work*, 2015;60(3):228-237. 442 licensed social workers' from across the U.S. responded to an online administration of the Religious/Spiritually Integrated Practice Assessment Scale. <http://sw.oxfordjournals.org/content/60/3/228.abstract?sid=0d553a37-2746-44d1-bddc-ddee01a4ae30>

How doctors want to die is different than most people

CNN | Online – 11 August 2015 – Dr. Kendra Fleagle Gornitsky recalls the anguish she used to feel performing CPR on elderly, terminally ill patients. "I felt like I was beating up people at the end of their life," she says. It looks nothing like what people see on TV. In real life, ribs often break and few survive the ordeal. Gornitsky now teaches medicine at the University of Southern California and says these early clinical experiences have stayed with her. "I would be doing the CPR with tears coming down sometimes, and saying, 'I'm sorry, I'm sorry, goodbye.' Because I knew it very likely was not going to be successful. It just seemed a terrible way to end someone's life." Gornitsky wants something different for herself and for her loved ones. And most other doctors do too: A Stanford University study shows almost 90% of doctors would forgo resuscitation and aggressive treatment if facing a terminal illness.¹ It was about 10 years ago, after a colleague had died swiftly and peacefully, that Dr. Ken Murray first noticed doctors die differently than the rest of us. "He had died at home, and it occurred to me that I couldn't remember any of our colleagues who had actually died in the hospital," Murray says. "That struck me as quite odd, because I know that most people do die in hospitals." Murray began talking about it with other doctors. "And I said, 'Have you noticed this phenomenon?' They thought about it, and they said, 'You know? You're right.'" <http://www.cnn.com/2015/08/10/health/how-doctors-want-to-die/>

1. "Do unto others": Doctors' personal end-of-life resuscitation preferences and their attitudes toward advance directives,' *PLoS One*, 28 May 2014. [Noted in Media Watch, 2 June 2014, #360 (p.11)] <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0098246>

Cont.

Physician perspectives on end-of-life care noted in past issues of Media Watch:

- 'How doctors die: Showing others the way,' *The New York Times* (U.S.), 19 November 2013 [Noted in Media Watch, 25 November 2013, #333 (p.5)] <http://www.nytimes.com/2013/11/20/your-money/how-doctors-die.html>
- 'How to die like a doctor,' *Forbes* (U.S.), 7 March 2012 [Noted in Media Watch, 12 March 2012, #244 (p.3)] <http://www.forbes.com/sites/carolynmcclanahan/2012/03/07/how-to-die-like-a-doctor/>
- 'Doctors do die differently...,' *Forbes* (U.S.), 2 March 2012 [Noted in Media Watch, 5 March 2012, #243 (p.2)] <http://www.forbes.com/sites/carolynmcclanahan/2012/03/02/doctors-do-die-differently-how-we-make-certain/>
- 'How doctors choose to die,' *The Guardian* (U.K.), 19 February 2012 [Noted in Media Watch, 27 February 2012, #242, p.8] <http://www.guardian.co.uk/theguardian/shortcuts/2012/feb/19/death-and-dying-doctors>
- 'Why MOST doctors like me would rather DIE than endure the pain of treatment we inflict on others for terminal diseases: Insider smashes medicine's big taboo,' *The Daily Mail* (U.K.), 14 February 2012 [Noted in Media Watch, 27 February 2012, #242 (p.8)] <http://www.dailymail.co.uk/health/article-2100684/Why-doctors-like-die-endure-pain-treatment-advanced-cancer.html>
- 'What doctors know – and we can learn – about dying,' *Time Magazine* (U.S.), 16 January 2012 [Noted in Media Watch, 23 January 2012, #237 (p.2)] <http://ideas.time.com/2012/01/16/what-doctors-know-and-we-can-learn-about-dying/?xid=gonewsedit>

Failing patients with heart failure

THE NEW YORK TIMES | Online – 10 August 2015 – Heart disease is the world's No. 1 killer, despite advances in medical technology, as well as public health initiatives that have eased the burden of heart disease drastically. While one marvels at the progress, we often ignore how heart-disease patients die. Patients with heart disease are more likely to suffer excessively at the end of life than those with other conditions. While surveys show that people overwhelmingly want to die at home, patients with cardiovascular disorders are much less likely to do so than patients with other diseases, such as cancer. All heart disease, as it progresses, results in heart failure, or a gradual weakening of the heart. Patients commonly experience difficult breathing, extreme fatigue and swelling of their legs and abdomen. Heart failure is the leading cause of hospital admissions among those older than 65 years of age annually. And yet these patients rarely get high-quality end-of-life care, in part because it is so hard to predict how individual cases will play out. http://www.nytimes.com/2015/08/10/opinion/failing-patients-with-heart-failure.html?_r=0

Noted in Media Watch, 13 July 2015, #418 (p.10):

- *AMERICAN HEART JOURNAL* | Online – 2 July 2015 – '**Unique challenges of hospice for patients with heart failure: A qualitative study of hospice clinicians.**' From a hospice clinician perspective, caring for patients with heart failure is unique compared to other hospice populations. This study suggests potential opportunities for hospice clinicians and referring providers who seek to collaborate to improve care for patients with heart failure during the transition to hospice care. [http://www.ahjonline.com/article/S0002-8703\(15\)00393-2/abstract](http://www.ahjonline.com/article/S0002-8703(15)00393-2/abstract)
- *BRITISH JOURNAL OF CARDIAC NURSING* | Online – 3 July 2015 – '**Understanding palliative care needs in heart failure.**' Clinicians often struggled to discuss palliation with heart failure patients owing to the unclear disease trajectory and cardiac-specific barriers to identifying palliation needs. <http://www.magonlinelibrary.com/doi/abs/10.12968/bjca.2015.10.7.348>
- *HEART FAILURE CLINICS*, 2015;11(3):479-498. '**Team-based palliative and end-of-life care for heart failure.**' Clinical practice guidelines endorse the use of palliative care in patients with symptomatic heart failure. The optimal content and delivery of palliative care interventions remains unknown and its integration into existing heart failure disease management continues to be a challenge. [http://www.heartfailure.theclinics.com/article/S1551-7136\(15\)00024-0/abstract](http://www.heartfailure.theclinics.com/article/S1551-7136(15)00024-0/abstract)

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 August 2015 – ‘**Does diagnosis make a difference? Comparing hospice care satisfaction in matched cohorts of heart failure and cancer caregivers.**’ The diagnosis of heart failure, in and of itself, does not appear to make a difference in informal caregiver satisfaction with hospice care. Significant differences were found in caregiver teaching, emotional support, coordination of care, and global satisfaction prior to matching, but the effect sizes were small. All differences disappeared after matching. High rates of dissatisfaction with caregiver teaching (42%) and emotional support (30%) were found in both cohorts. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0078>

N.B. Selected articles on palliative care in patients with heart failure noted in past issues of Media Watch are listed in the issue of the weekly report dated 19 January 2015, #393 (pp.11-12).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | CBS News (San Francisco) – 14 August 2015 – ‘**California ban on doctor-assisted suicide upheld in San Francisco court.**’ A Superior Court judge upheld the enforcement of California laws dating back 141 years barring physician-assisted suicide after hearing arguments in a lawsuit filed by several terminally ill patients. The judge expressed concern about the possibility that, if the law was changed, a patient who is suffering financially from a terminal illness would be able to choose to die simply because their family wasn’t able to afford their continued medical expenses. <http://sanfrancisco.cbslocal.com/2015/08/14/california-ban-on-doctor-assisted-suicide-upheld-in-san-francisco-court/>
- NEW MEXICO | KOB-TV News (Albuquerque) – 11 August 2015 – ‘**New Mexico Court of Appeals strikes down right-to-die ruling.**’ The New Mexico Court of Appeals struck down a prior Bernalillo County District Court ruling that essentially allowed assisted suicide in the state. District Court Judge Nan Nash previously ruled that a 1963 state statute making assisted suicide a fourth-degree felony in the state was invalid as applied to physicians who administer a lethal dose of medication to a terminally-ill patient. “This Court cannot envision a right more fundamental, more private or more integral to the liberty, safety and happiness of a New Mexican than the right of a competent, terminally ill patient to choose aid in dying,” Nash wrote at the time. The court’s decision at the time ruled that aid in dying was a fundamental liberty, however, the Court of Appeals reversed that ruling in Tuesday’s decision. The Court of Appeals also reverse the district court’s decision to stop the state from enforcing the 1963 law. The Court of Appeals also instructed district courts to stop proceedings in further assisted suicide and right-to-die cases. <http://www.kob.com/article/stories/s3876640.shtml#.VcuTUv9RGos>

International

End-of-life care in Ireland

Terminally ill need not die in hospital, says study

IRELAND | *The Irish Times* (Dublin) – 14 August 2015 – The number of people dying in hospital could be substantially reduced through the provision of more hospices or specialist care at home, according to a new report.¹ Wide variations in access to care for the terminally ill exist across different regions... Despite high overall levels of satisfaction with services, patients had a preference for palliative care delivered in specialist units over hospital care. Costs were similar in different areas of the country, despite the differences in the level and type of services provided, the researchers ... found. The study, which looked at palliative care services in the Health Service Executive midlands, mid-west and southeast, found not all areas had access to specialist palliative care inpatient units, daycare centres or hospice care. Availability of services varied from 24 hours a day, seven days a week, to office hours only. <http://www.irishtimes.com/news/health/terminally-ill-need-not-die-in-hospital-says-study-1.2316486>

Cont.

1. 'Economic Evaluation of Palliative Care in Ireland,' from Trinity College Dublin and the Economic and Social Research Institute, August 2015. The report was prepared for The Atlantic Philanthropies. <http://www.esri.ie/UserFiles/publications/BKMNEXT295.pdf>

Noted in Media Watch, 28 October 2013, #329 (p.5):

- IRELAND | *The Irish Times* (Dublin) – 22 October 2013 – '**Lack of hospice beds leaves terminal patients out in the cold.**' More than a decade ago a report from the National Advisory Committee on Palliative Care recommended there should be one hospice bed per 10,000 of the population.¹ According to the latest report from the Irish Hospice Foundation,² just "just two regions come close to fulfilling government policy." <http://www.irishtimes.com/life-and-style/health-family/lack-of-hospice-beds-leaves-terminal-patients-out-in-the-cold-1.1568194>
 1. *Report of the National Advisory Committee on Palliative Care*, Department of Health & Children, 2001. <http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1>
 2. *Access to Specialist Palliative Care Services & Place of Death in Ireland...* Irish Hospice Foundation, May 2013. <http://hospicefoundation.ie/wp-content/uploads/2013/06/Access-to-specialist-palliative-care-services-place-of-death-in-Ireland.pdf>

Noted in Media Watch, 21 January 2013, #289 (p.4):

- IRELAND | The Atlantic Philanthropies – 17 January 2013 – '**Evaluation: Programme to Support Palliative & Hospice Care in the Republic of Ireland.**' There has been significant expansion in palliative care services in Ireland over the last 25 years, although gaps in provision remain. This report presents the findings of a five-phased evaluation of the programme. [http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation Programme Support Palliative and Hospice Care %20Republic of Ireland.pdf](http://www.atlanticphilanthropies.org/sites/default/files/uploads/Evaluation%20Programme%20Support%20Palliative%20and%20Hospice%20Care%20Republic%20of%20Ireland.pdf)

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.

Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Care homes in Ireland

Inspectors find failings in every Health Service Executive disability care home

IRELAND | *The Irish Times* (Dublin) – 13 August 2015 – More than 93% of inspections of disability homes carried out by the State’s health watchdog found the facilities failed to comply with national standards. An analysis [by *The Irish Times*] of more than 900 inspection reports published since the Health Information & Quality Authority (HIQA) began inspecting such facilities in November 2013 shows that HSE-run disability homes fare particularly badly. HIQA assesses disability homes against up to 18 standards during each inspection, including residents’ rights, health-care needs and welfare needs as well as staffing levels, medication management and governance. <http://www.irishtimes.com/news/social-affairs/inspectors-find-failings-in-every-hse-disability-care-home-1.2315327>

Elder and End-of-life care in the U.K.

Hospitals act like “conveyor belts” for dying patient

U.K. (England) | *The Daily Telegraph* – 13 August 2015 – Nearly half of hospitals are putting dying patients at risk of harm or unnecessary suffering, the care watchdog has warned as it said those with conditions like dementia and heart disease are receiving a poorer standard of treatment. The Care Quality Commission (CQC) revealed that 50 of the 105 hospitals it has inspected since November 2013 have been criticised over patient safety.¹ They include hospitals where dying patients were referred to by their bed numbers instead of their names and doctors issued “do not resuscitate” orders without informing those being treated. In other instances patients were left for hours without painkillers or faced huge delays in accessing transport to take them home to die. By contrast almost nine in 10 hospices were found to be providing good or outstanding levels of care. The CQC said it is so concerned by

the findings that it is launching a “thematic review” to establish why people with dementia and those dying from illnesses other than cancer receive a poorer standard of care. <http://www.telegraph.co.uk/news/nhs/11802113/Hospitals-act-like-conveyor-belts-for-dying-patients.html>

Specialist Publications

‘The impact of a new public health approach to end-of-life care: A systematic review’ (p.17), in *Palliative Medicine*.

‘Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care’ (p.19), in *Palliative Medicine*.

1. ‘One Chance to Get it Right: One Year On Report,’ Care Quality Commission, August 2015. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450391/One_chance_-_one_year_on_acc.pdf

N.B. ‘One Chance to Get it Right: Improving People’s Experience of Care in the Last Few Days and Hours of Life,’ Leadership Alliance for the Care of Dying People, June 2014. [Noted in *Media Watch*, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

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Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Of related interest:

- U.K. (Wales) | BBC News – 11 August 2015 – **‘Elderly care home review responses “disappointing,”**’ Care inspectors and ministers have been criticised for failing to explain in detail how they will improve life for elderly people in care homes. Older People’s Commissioner Sarah Rochira said she was “disappointed” with their responses to a 2014 review.¹ It found elderly residents “quickly become institutionalised” in homes seen as places of “irreversible decline.” The Welsh government said it was taking “strong action” with new laws to improve the regulation of care homes. <http://www.bbc.com/news/uk-wales-politics-33853282>
 1. ‘A Place to Call Home? A Review into the Quality of Life and Care of Older People Living in Care Homes in Wales,’ Older People’s Commissioner for Wales (Comisiynydd Pobl Hyn Cymru), 10 November 2014. [Noted in Media Watch, 17 November 2014, #384 (p.5)] http://www.olderpeoplewales.com/en/Reviews/Residential_Care_Review/ReviewReport.aspx
- U.K. (England) | *The Guardian* – 8 August 2015 – **‘Cash-starved, demoralised and sometimes cruel: How England’s social care system fails the most vulnerable.’** With more than £4 billion slashed from funding, care workers are being forced to cut corners to deal with a growing ageing population. So should we be surprised allegations of abuse and neglect have now hit record levels? The Care Quality Commission (CQC) revealed regulators were notified of 30,000 allegations of abuse involving people using social care services in the first six months of this year. The rate at which allegations of abuse have been made in 2015 is double that of 2011. The increased frequency of allegations can in part be explained by an improved performance by the CQC in recording abuse. <http://www.theguardian.com/society/2015/aug/08/social-care-england-elderly-budget-cuts>

N.B. Care Quality Commission website: <http://www.cqc.org.uk/>

Turkey looks to expand hospital palliative care

TURKEY | *The Daily Sabah* (Istanbul) – 11 August 2015 – The Health Ministry aims to boost palliative care for patients with serious illnesses and their relatives by establishing palliative care units at 227 public hospitals. The units will be integrated into the health system, whereas previously it was a complementary facility... A total of 3,258 beds were previously allocated for palliative care units, and there are currently 67 palliative care units, staffed with doctors, nurses, psychiatrists, dietitians, social service workers and physiotherapists. Though not exactly palliative care, Turkey began deploying imams as spiritual counselors at hospitals for critically ill patients and their families earlier this year. <http://www.dailysabah.com/nation/2015/08/12/turkey-looks-to-expand-hospital-palliative-care>

Noted in Media Watch, 30 March 2015, #403 (p.16):

- *JOURNAL OF PUBLIC HEALTH MANAGEMENT & PRACTICE* | Online – 13 March 2015 – **‘Community palliative care in Turkey: A collaborative promoter to a new concept in the Middle East.’** The Middle East has been struggling with basic issues of cancer care, and in specific, palliative care, at the primary health care level in the communities. The Middle East Cancer Consortium designated this issue as the highest priority of its activities in the region. http://journals.lww.com/jphmp/Abstract/publishahead/Community_Palliative_Care_in_Turkey_A.99765.aspx

Noted in Media Watch, 11 June 2012, #257 (p.8):

- *ANNALS OF ONCOLOGY*, 2012;23(Suppl3):76-78. **‘Turkish community-based palliative care model: A unique design.’** One of the pillars of the Turkish Cancer Control Programme is palliative care. The Pallia-Turk project is population based and organized at the primary level. This means, the whole population of 70 million will have the quickest and easiest way for access to palliative care. http://annonc.oxfordjournals.org/content/23/suppl_3/76.abstract

N.B. Turkey was rated 34th (of the 40 countries surveyed) in *The Quality of Death: Ranking End-of-Life Care Across the World*, commissioned by The Lien Foundation and published by the Economist Intelligence Unit, 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

No matter the species

The vet will see you now...

U.K. (England) | BBC News – 9 August 2015 – How does the care and compassion shown to animals when they are sick compare to the treatment patients receive in the National Health Service (NHS)? There are, of course, a number of important differences between the care humans and animals receive. In the U.K., veterinary care is not free at the point of delivery whereas in the NHS, every human patient is treated equally according to their need and not their bank balance. Arguably, the health system is under severe strain as a result. Dealing with complex human beings is very different to dealing with sick animals, but it has been suggested that lessons could be learned from watching how vets organise and deliver care and, particularly, how animals are looked after at the end of their lives. <http://www.bbc.com/news/health-33802686>

End-of-life care in Scotland

Children's hospices hit by cut to funding

U.K. (Scotland) | *The Sunday Express* – 9 August 2015 – Children's hospices have suffered a severe cut to funding levels under the Scottish National Party (SNP)... The Children's Hospice Association Scotland (CHAS) will spend more than £10 million this year on caring for terminally ill youngsters at Rachel House in Kinross and Robin House in Balloch, Dunbartonshire. National Health Service (NHS) Scotland is contributing only £691,000, or 6.7%, to the charity's running costs. Although the cash sum has increased from last year, the percentage contribution has fallen from 6.9%. Under a separate agreement with the ... Convention of Scottish Local Authorities, Scotland's 32 local authorities jointly pay £700,000 a year to CHAS. In total, this amounts to only 13.5% of this year's running costs. This is despite a written instruction from the Scottish Government that health boards and councils "will jointly meet 25% of the running costs of the independent children's hospices." According to CHAS's 2006/2007 accounts, the last year before the SNP came to power, statutory funding from health boards and local authorities "increased to 22.4%." <http://www.express.co.uk/news/uk/597086/Children-s-hospices-hit-by-cut-to-funding-SNP>

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 in Scotland facing an uncertain future, as they leave the comfort of children's services behind. CHAS ... has introduced a policy to assist young people during this transition. <http://rcnpublishing.com/doi/pdfplus/10.7748/ncyp2014.02.26.1.8.s9>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *The Daily Telegraph* – 14 August 2015 – **“There is nothing sacred about suffering,” insist faith leaders in assisted dying call.** Religious teachings that elevate suffering and pain as something “sacred” should not be used to prevent terminally ill people taking their own lives, leading Christian and Jewish clerics have insisted. An alliance of bishops, priests and rabbis have broken ranks with the religious establishment to voice support for plans to change the law to allow a form of assisted suicide in the U.K. for the first time. In a letter to *The Daily Telegraph*, they argue that far from being a sin, helping terminally ill people to commit suicide should be viewed simply as enabling them to “gracefully hand back” their lives to God. <http://www.telegraph.co.uk/news/religion/11803955/There-is-nothing-sacred-about-suffering-insist-faith-leaders-in-assisted-dying-call.html>

Cont.

- REUTERS | Online – 10 August 2015 – ‘**European doctors often reject assisted-suicide requests.**’ Even when physician-assisted suicide is legal, doctors often have reservations about helping patients die, two European studies suggest. In one study,¹ researchers reviewed euthanasia requests made to the End-of-Life Clinic, established in The Netherlands in 2012 to provide the option of physician-assisted suicide to people who met legal requirements for this possibility, but couldn’t convince their regular physicians to approve it. The clinic granted just 25% of the 645 requests received from March 2012 to March 2013. To legally assist with suicide in The Netherlands doctors must, among other things, verify that the patient is making the request voluntarily, has unbearable suffering without any prospects for improvement, and fully understands his or her situation... These requirements may explain why doctors in the study were more willing to approve euthanasia requests from patients with physical suffering, tied to conditions such as cancer and cardiovascular disease, than from people seeking suicide help only for psychological problems, she added. In a related study² ... researchers surveyed doctors in Flanders, Belgium, and found the prevalence of physician-assisted suicides increased from 1.9% of all deaths in 2007 to 4.6% in 2013. <http://www.reuters.com/article/2015/08/10/us-health-suicide-physician-assisted-idUSKCN0QF1QC20150810>
 1. ‘A study of the first year of the end-of-life clinic for physician-assisted dying in The Netherlands,’ *JAMA Internal Medicine*, 10 August 2015. Analysis of application forms and registration files from 1 March 2012, to 1 March 2013 ... for 645 patients who applied to the clinic with a request for euthanasia or physician-assisted suicide and whose cases were concluded during the study period. <http://archinte.jamanetwork.com/article.aspx?articleid=2426428>
 2. ‘Comparison of the expression and granting of requests for euthanasia in Belgium in 2007 vs 2013,’ *JAMA Internal Medicine*, 10 August 2015. This study examined shifts in the expression and granting of euthanasia requests 2007-2013 and the reasons that physicians granted or denied these requests. <http://archinte.jamanetwork.com/article.aspx?articleid=2426426>

N.B. ‘Euthanasia in Belgium and The Netherlands: On a slippery slope’ (Commentary), *JAMA Internal Medicine*, 10 August 2015. <http://archinte.jamanetwork.com/article.aspx?articleid=2426425>

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

Aggregating hospice

Impact of a centralized inpatient hospice unit in an academic medical center

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 August 2015 – Rush University Medical Center [RUMC] and Horizon Hospice opened the first centralized inpatient hospice unit (CIPU) in a Chicago academic medical center in 2012. This study examined if there was a difference in cost or length of stay (LOS) in a CIPU compared to hospice care in scattered beds [SBM]... The CIPU patients had longer hospice LOS days [6.0 vs. 2.0 days for SBM patients] but lower hospital costs. Academic medical centers may benefit from aggregating hospice beds. <http://ajh.sagepub.com/content/early/2015/08/13/1049909115599157.abstract>

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

Evolving the palliative care workforce to provide responsive, serious illness care evolving the palliative care workforce

ANNALS OF INTERNAL MEDICINE | Online – 11 August 2015 – The U.S. is currently in the midst of a national crisis in providing accessible and responsive palliative care due to a shortage of professionals trained to provide this care. The authors suggest one possible approach for dealing with this crisis. <http://annals.org/article.aspx?articleid=2424874>

Cont.

Of related interest:

- *JOURNAL OF CLINICAL NURSING* | Online – 10 August 2015 – ‘**Fluid role boundaries: Exploring the contribution of the advanced nurse practitioner to multi-professional palliative care.**’ The advanced nurse practitioner has potential to enhance specialist palliative care service delivery through fluid role boundaries. The context in which their roles are developed is important as acceptance of the role is linked to the co-construction of a different nursing identity. <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12950/abstract;jsessionid=7D372766D3CD9256BB6D21692D845450.f02t02?userIsAuthenticated=false&deniedAccessCustomisedMessage>

Developing a computerised search to help U.K. general practices identify more patients for palliative care planning: A feasibility study

BMC FAMILY PRACTICE | Online – 8 August 2015 – Recent controversies over the care of patients thought to be at the end of life should cause us to consider the benefits and potential harms of identifying relevant individuals, as well as how we can do it better. A badly-designed and implemented computer search would rightly attract negative press attention if it focused on planning for “dying” rather than helping people live as well as possible to the end of their life. On the other hand, an electronic search tool that enables primary care clinicians to identify more patients who might benefit from anticipatory care planning and regular review could help address current inequities in the provision of supportive and palliative care in the community, and lessen the risk of under-informed decision making... <http://www.biomedcentral.com/content/pdf/s12875-015-0312-z.pdf>

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

- *PALLIATIVE MEDICINE* | Online – 13 November 2014 – ‘**Promoting palliative care in the community: Production of the primary palliative care toolkit by the European Association of Palliative Care Taskforce in primary palliative care.**’ Being unable to identify appropriate patients for palliative care in the community is a major barrier internationally. The systematic review identified tools that might be used to help address this. A primary palliative care toolkit has been produced and refined, together with associated guidance. Many barriers and facilitators were identified. <http://pmj.sagepub.com/content/early/2014/11/12/0269216314545006.abstract>

Noted in Media Watch, 25 November 2013, #333 (p.10):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2013;3(4):444-451. ‘**What tools are available to identify patients with palliative care needs in primary care: A systematic literature review and survey of European practice.**’ A structured method or tool may be useful to help general practitioners identify patients for early palliative care and trigger assessment and care planning. Although several identification tools have been developed, none of these have been validated or widely implemented in Europe. <http://spcare.bmj.com/content/3/4/444.short>

End-of-life care in rural communities

Creating capacity through partnership: A palliative care skills development programme

BRITISH JOURNAL OF COMMUNITY NURSING | Online – 7 August 2015 – This paper presents the development and implementation of a recurrently funded, rolling, six-month palliative care secondment programme for National Health Service community staff nurses based in a rural health economy in Southwest England. The programme is a key tool in a wider plan for improving access to, and the quality of, palliative and end-of-life care for a dispersed rural population. This is part of a ... programme of integration to meet the shared challenges of service capacity, equity, and sustainability that are presented by the geographical and demographical profile of the locality. The “bigger picture” is defined and set in the context of the national drive and evidence base for integration in order to explain the reasons behind the secondment programme. <http://www.magonlinelibrary.com/doi/abs/10.12968/bjcn.2015.20.8.370>

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Representative sample of articles noted in past issues of Media Watch on the provision and delivery of end-of-life care in rural areas.

- *RURAL & REMOTE HEALTH* | Online – 24 June 2014 – ‘**Nurses’ experiences providing palliative care to individuals living in rural communities: Aspects of the physical residential setting.**’ Nurses described the characteristics of working in a rural community and how it influences their perception of their role, highlighting the strong sense of community that exists, but how system changes over the past decade have changed the way they provide care. They also described the key role that they play, which was often termed a “jack of all trades,” but focused on providing emotional, physical, and spiritual care while trying to manage many challenges related to transitioning and working with other healthcare providers. [Noted in Media Watch, 30 June 2014, #364 (p.15)] <http://www.rrh.org.au/articles/printviewnew.asp?ArticleID=2728>
- *RURAL & REMOTE HEALTH* | Online – 14 May 2014 – ‘**Understanding the distinct experience of rural inter-professional collaboration in developing palliative care programs.**’ Previous research on developing rural palliative care has created a four-phase capacity development model that included inter-professional rural palliative care teams; however, the details of rural team dynamics had not been previously explored and defined. [Noted in Media Watch, 19 May 2014, #358 (p.10)] <http://www.rrh.org.au/articles/subviewnew.asp?ArticleID=2711>
- *RURAL & REMOTE HEALTH* | Online – 7 January 2013 – ‘**Comparing the experiences of rural and urban family caregivers of the terminally ill.**’ Few studies have explored the experience of palliative care in rural settings. Urban and rural caregivers reported similarly high levels of social support. Rural caregivers reported greater use of family physicians, emergency room visits and pharmacy services, while urban caregivers reported greater use of caregiver respite services. Results suggest that while there are commonalities to the caregiving experience regardless of setting, key differences also exist. [Noted in Media Watch, 14 January 2013, #388 (p.13)] <http://www.rrh.org.au/articles/showarticlenew.asp?ArticleID=2250>

End-of-life care in Germany

Place of death: Trends over the course of a decade: A population-based study of death certificates from the years 2001 and 2011

DEUTSCHES ÄRZTEBLATT INTERNATIONAL, 2015;112(29-30):496-504. In Germany, data on place of death is recorded from death certificates, but not further analyzed. The authors analyzed 24,009 death certificates (11,585 for 2001 and 12,424 for 2011). The distribution of places of death for the overall population was as follows (2001 vs. 2011): at home, 27.5% vs. 23.0%; in the hospital, 57.6% vs. 51.2%; on a palliative care unit, 0.0% vs. 1.0%, in a care or nursing home, 12.2% vs. 19.0%; in a hospice, 2.0% vs. 4.6%; elsewhere, 0.6% vs. 0.6%; not indicated, 0.1% vs. 0.6%. Independent factors affecting the place of death were age, sex, place of residence, and the presence of cancer or of dementia. Most people in Germany die in institutions; the most common place of death is still the hospital, where more than half of all deaths take place. Only one death in four occurs at home. There is a marked secular trend away from dying at home or in the hospital, in favor of dying in a care or nursing home; death in palliative care units and hospices is also becoming more common. <https://www.aerzteblatt.de/int/archive/article?id=171327>

Noted in Media Watch, 3 November 2014, #382 (p.10):

- *CANCER*, 2014;120(20):3254-3260. ‘**Dying in cancer centers: Do the circumstances allow for a dignified death?**’ Prior research has shown that hospitals are often ill-prepared to provide care for dying patients. This study assessed whether the circumstances for dying on cancer center wards [in 16 hospitals belonging to 10 cancer centers in Baden-Wuerttemberg, Germany] allow for a dignified death. Half of the participants indicated that they rarely have enough time to care for dying patients, and 55% found the rooms available for dying patients unsatisfactory. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.28702/abstract>

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

Guardianship and end-of-life decision making

JAMA INTERNAL MEDICINE | Online – 10 August 2015 – As the population ages, more adults will develop impaired decision-making capacity and have no family members or friends available to make medical decisions on their behalf. In such situations, a professional guardian is often appointed by the court. This official has no pre-existing relationship with the impaired individual but is paid to serve as a surrogate decision maker. When a professional guardian is faced with decisions concerning life-sustaining treatment, substituted judgment may be impossible, and reports have repeatedly suggested that guardians are reluctant to make the decision to limit care. Physicians are well positioned to assist guardians with these decisions and safeguard the rights of the vulnerable persons they represent. Doing so effectively requires knowledge of the laws governing end-of-life decisions by guardians. However, physicians are often uncertain about whether guardians are empowered to withhold treatment and when their decisions require judicial review. To address this issue, the authors analyzed state guardianship statutes and reviewed recent legal cases to characterize the authority of a guardian over choices about end-of-life treatment. They found that most state guardianship statutes have no language about end-of-life decisions. The authors identified 5 legal cases during the past decade that addressed a guardian's authority over these decisions, and only 1 case provided a broad framework applicable to clinical practice. <http://archinte.jamanetwork.com/article.aspx?articleid=2426429>

Noted in Media Watch, 26 January 2015, #394 (p.10):

- *DISABILITIES STUDY QUARTERLY*, 2014;34(4). **'Determining "best interests" in end-of-life decisions for the developmentally disabled: Minnesota state guardians and wards.'** The authors review the legal cases, legislative statutes, and professional standards that guide public guardians in deciding whether to begin, continue, or withdraw or withhold life-sustaining medical treatment from their wards. In particular, they reveal how the guardians' recommendations to the state Public Guardianship Administrator include such ableist assumptions as "normal," "natural," and "reasonable," but they also recognize the guardians' resistance to mind/body dichotomies and their expertise in determining quality of life in the context of how their wards live those lives. <http://dsq-sds.org/article/view/4276/3797>

Noted in Media Watch, 18 March 2013, #297 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 March 2013 – **'Hardships of end-of-life care with court-appointed guardians.'** This article reviews the hardships that patients, court-appointed guardians, and health care staff endure while moving through the oppressive process of obtaining end-of-life (EOL) care orders through the court. The author proposes ways of tuning up the laws, regulations, and communications to make it easier and faster to obtain orders regarding EOL care to preserve the dignity of our patients and loved ones. <http://ajh.sagepub.com/content/early/2013/03/01/1049909113481100.abstract>

The benefits of a nurse-driven, patient- and family-centered pediatric palliative care program

JOURNAL OF NURSING ADMINISTRATION | Online – 6 August 2015 – This article describes the ... outcomes of a nurse driven, patient- and family-centered pediatric advanced comprehensive care team (PACCT) palliative program. This ... model improved patient outcomes by providing care across the healthcare continuum for pediatric patients. Since the inception of PACCT, no child has died on a ventilator in the pediatric ICU associated with end of life-related issues. http://journals.lww.com/jonajournal/Abstract/publishahead/The_Benefits_of_a_Nurse_Driven_Patient_and.99975.aspx

Adding value to palliative care services: The development of an institutional bereavement program

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 August 2015 – The elevated risk of serious physical and mental health problems among the bereaved is a strong argument for the development of universal institution-based bereavement programs as an element of quality care for family members of all patients who die. The authors describe the development of the program at Dana-Farber Cancer Institute where they conceptualized bereavement services as a preventive model of care. Bereavement programs can both help bereaved individuals adapt to their loss, and positively impact hospitals by enhancing the reputation of the hospital within the community and providing an avenue for identifying opportunities for improvement in care processes. The authors recommend that all hospitals implement basic bereavement programs for families of all deceased patients as the standard of care. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0080>

The serendipitous survey: A look at primary and specialist palliative social work practice, preparation, and competence

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 August 2015 – Health professionals have begun to identify competencies needed for primary and specialist levels of palliative care practice, but little attention has been given to how these skills are acquired. A representative sample of social workers practicing in health care identify high competence in essential aspects of palliative care. This speaks to an existing pool of clinicians who, if practicing to the top of their licenses, have the potential to provide primary palliative care and contribute to the person-family centered care called for in the Institute of Medicine report.¹ Few programs exist to prepare social workers to work as specialists in palliative or end-of-life settings, and respondents identified key areas of practice that need to be integrated into graduate education to ensure that students, practitioners, and educators are better prepared to maximize the impact of health social work. Further research is needed to better understand how to prepare and train specialist-level palliative care social workers. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0022>

1. 'Dying in America: Improving Quality & 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>

N.B. 'Core competencies for palliative care social work in Europe: A European Association for Palliative Care White paper: Part 1 [Noted in Media Watch, 10 November 2014, #383 (p.12)]; Part 2 [Noted in Media Watch, 26 January 2015, #394 (p.10)], *European Journal of Palliative Care*. Access requires a subscription. Journal home page: <http://www.haywardpublishing.co.uk/ejpc.aspx>

Developing organisational ethics in palliative care: A three-level approach

NURSING ETHICS | Online – 14 August 2015 – Palliative carers constantly face ethical problems. There is lack of organised support for the carers to handle these ... in a consistent way. Within organisational ethics, the authors find models for moral deliberation and for developing organisational culture; however, they are not combined in a structured way to support carers' everyday work. In this study, the authors found six categories of ethical problems (with the main focus on problems relating to the patient's loved ones) and five categories of organisational obstacles. They developed a set of values: 1) A general level; 2) An explanatory level; and, 3) A level of action strategies. The ethical problems found corresponded to problems in other studies with a notable exception, the large focus on patient loved ones. The three-level set of values is a way to handle risks of formulating abstract values not providing guidance in concrete care voiced in other studies. <http://nej.sagepub.com/content/early/2015/08/13/0969733015595542.abstract>

Patients feeling severely affected by multiple sclerosis: Addressing death and dying

OMEGA – JOURNAL OF DEATH & DYING | Online – 13 August 2015 – Eleven months after being interviewed in a study on unmet needs of severely affected multiple sclerosis patients, one participant died by assisted suicide. The authors reanalyzed the data to find out if the 15 study patients might have brought up the topic of death and dying during episodic interviews that had not primarily addressed this issue. Secondary analysis with regard to the thematic field of death and dying revealed that patients unsolicited brought up this issue within the following categories: “Passing over death and dying,” “Death is not relevant to me,” “We want to keep up the life challenge,” “Death as an option,” and “Wish to have the opportunity to address end-of-life issues.” The authors conclude that the topic of death and dying is of importance to these patients... Health professionals should individually acknowledge patients’ needs to address death and dying. <http://ome.sagepub.com/content/early/2015/08/12/0030222815598443.abstract>

Noted in Media Watch, 12 March 2012, #244 (p.12)

- *JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY*, 2012;83(3):e1. ‘**Attitudes towards end-of-life issues among people with multiple sclerosis.**’ The authors sought to explore the attitudes towards end-of-life issues among people with multiple sclerosis (MS) and motor neurone disease (MND) via online surveys. Advance decisions: 12% of people with MS (PwMS) and 75% of people with MND (PwMND) had written an advance decision; 51% PwMS wanted more information. Mood: 34% of PwMS and 51% of PwMND had considered suicide since their diagnosis; 64% of PwMS and 65% of PwMND would like the healthcare team to ask about their mood. Assisted suicide and dying: 77% of PwMS and 85% of PwMND believed in the right to choose how and when we die; 77% of PwMS and 71% of PwMND believed that assisted suicide should be legalised in their country; 31% of PwMS and 22% of PwMND had considered going abroad for assisted suicide. Communication and the doctor–patient relationship: 7% of PwMS and 43% of PwMND had discussed such issues with a doctor or nurse; 21% of PwMS and 53% of PwMND wished to do so; 51% of people with both PwMS and PwMND considered it not a problem if their clinician was involved in assisted suicide; a further 28% of PwMS and 21% of PwMND felt it would not affect the treatment of their condition. <http://jnnp.bmj.com/content/83/3/e1.78.abstract?sid=2d78f642-d629-4e9d-a43d-5561f4889829>

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

The impact of a new public health approach to end-of-life care: A systematic review

PALLIATIVE MEDICINE | Online – 12 August 2015 – Interest is building regarding the application of the principles of the new public health approach to those facing the end of life and their families and communities. Three main themes emerged from the meta-ethnography: 1) Making a practical difference; 2) Individual learning and personal growth; and, 3) Developing community capacity. The quantitative findings mapped to the meta-ethnography and demonstrated that engaging communities can lead to improved outcomes for carers such as decreased fatigue or isolation, increase in size of caring networks and that wider social networks can influence factors such as place of death and involvement of palliative care services. Impact assessment should be an integral part of future initiatives and policy makers should recognise that these approaches can influence complex issues such as carer support, community capacity, wellbeing and social isolation. <http://pmj.sagepub.com/content/early/2015/08/04/0269216315599869.abstract>

From the archives:

- *BRITISH MEDICAL JOURNAL* | Online – 26 January 2014 – ‘**Public health approaches to end-of-life care in the U.K.: Online survey of palliative care services.**’ Of those providers [of palliative care services who responded, 60% indicated that public health approaches to death, dying and loss were a priority for their organisation. Respondents identified a range of work being undertaken currently in this area. The most successful were felt to be working with schools and working directly with local community groups. Various challenges were highlighted. http://www.academia.edu/7838782/Public_health_approaches_to_end-of-life_care_in_the_UK_an_online_survey_of_palliative_care_services

Doctors discussing religion and spirituality: A systematic literature review

PALLIATIVE MEDICINE | Online – 12 August 2015 – The authors set out to answer the following research questions: Do doctors report that they ask their patients about religion and/or spirituality and how do they do it? According to doctors, how often do patients raise the issue of religion and/or spirituality in consultation and how do doctors respond when they do? What are the known facilitators and barriers to doctors asking their patients about religion and/or spirituality? Overall, 61 eligible papers were identified, comprising over 20,044 physician reports. Religion and spirituality are discussed infrequently by physicians although frequency increases with terminal illness. Many physicians prefer chaplain referral to discussing religion and/or spirituality with patients themselves. Such discussions are facilitated by prior training and increased physician religiosity and spirituality. Insufficient time and training were the most frequently reported barriers.

<http://pmj.sagepub.com/content/early/2015/08/04/0269216315600912.abstract>

Of related interest:

- *PSYCHO-ONCOLOGY* | Online – 10 August 2015 – ‘**The effect of spiritual interventions addressing existential themes using a narrative approach on quality of life of cancer patients: A systematic review and meta-analysis.**’ Directly after the intervention, spiritual interventions had a moderate beneficial effect in terms of improving quality of life of cancer patients compared with that of a control group. No evidence was found that the interventions maintained this effect up to 3-6 months after the intervention. Further research is needed to understand how spiritual interventions could contribute to a long-term effect of increasing or maintaining quality of life. <http://onlinelibrary.wiley.com/doi/10.1002/pon.3910/abstract>

Selected articles on spirituality, in the context of end-of-life care, noted in past issues of Media Watch:

- *JOURNAL OF HEALTH PSYCHOLOGY* | Online – 28 May 2015 – ‘**Spirituality in patients with advanced illness: The role of symptom control, resilience and social network.**’ Statistically significant correlations were found between some dimensions of spirituality and poor symptomatic control, resiliency, and social support. [Noted in Media Watch, 8 June 2015, #413 (p.11)] <http://hpg.sagepub.com/content/early/2015/05/28/1359105315586213.abstract>
- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 25 May 2014 – ‘**Describing spirituality at the end of life.**’ The authors’ analysis of the literature identified five attributes that most commonly described the essence of spirituality: 1) Meaning; 2) Beliefs; 3) Connecting 4) self-transcendence; and, 5) Value. [Noted in Media Watch, 2 June 2014, #360 (p.12)] <http://wjn.sagepub.com/content/early/2014/05/23/0193945914535509.abstract>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(2-3). ‘**Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.**’ The theme of this issue of the journal is “theoretical and practice perspectives in which spirituality plays a key role in end-of-life care.” [Noted in Media Watch, 24 June 2013, #311 (p.12)] Journal contents page: <http://www.tandfonline.com/toc/wswe20/current>
- *ARCHIVE FOR THE PSYCHOLOGY OF RELIGION*, 2012;34(1):63-81. ‘**Six understandings of the word “spirituality” in a secular country.**’ A common understanding of the term does not exist, at least in a modern secular setting. Six understandings of spirituality were identified in this study: 1) positive dimensions in human life and well-being; 2) New Age ideology; 3) an integrated part of established religious life; 4) a vague striving, opposed to religion; 5) selfishness; and, 6) ordinary inspiration in human activities. [Noted in Media Watch, 25 June 2012, #259 (p.9)] <http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005>

Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care

PALLIATIVE MEDICINE | Online – Accessed 11 August 2015 – Eighty experts from 15 European countries evaluated 52 items within the following 13 norms: 1) Equity of access; 2) Communication; 3) Recognising the need for palliative care; 4) Assessment of total needs; 5) Symptom management; 6) End-of-life decision making; 7) Involving those who matter; 8) Collaboration; 9) Support for family/carers; 10) Preparing for death; 11) Bereavement support; 12) Education/training; and, 13) Developing/managing services. None of the items scored less than 86% agreement, making a further round unnecessary. In light of respondents' comments, several items were modified and one item was deleted. This White Paper presents the first guidance for clinical practice, policy and research related to palliative care for people with intellectual disabilities based on evidence and European consensus, setting a benchmark for changes in policy and practice. <http://eprints.kingston.ac.uk/32223/1/Tuffrey-Wijne-I-32223.pdf>

Noted in Media Watch, 27 July 2015, #420 (p.13):

- *BMC PALLIATIVE CARE* | Online – 25 July 2015 – ‘Shifts in care approaches at the end of life of people with intellectual disabilities: A qualitative study of the perspectives of relatives, care-staff and physicians.’ This paper describes the shifts in care approaches and attitudes that relatives and professionals perceive as the death of a person with intellectual disabilities (ID) approaches, as well as the values underlying these shifts... Six relational values were behind these shifts... End-of-life care for people with ID involves curtailing expectations of participation and skill acquirement, and an increase in teamwork featuring intensified comforting care, symptom management, and medical decision making. ID care services should invest particularly in the emotional support and expertise level of care staff, and in the collaboration between relatives and professionals. <http://www.biomedcentral.com/content/pdf/s12904-015-0030-2.pdf>

N.B. Articles on the palliative or end-of-life care needs of individuals with intellectual and developmental disabilities have been noted in several issues of Media Watch, for example, the issues of the weekly report of 2 February 2015, #395 (pp.10-11); 29 September 2014, #377 (pp.13-14); 2 June 2014, #360 (pp.10-11); and, 10 March 2014, #348 (pp.8-9).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *COLOMBIA MÉDICA*, 2015;46(2):52-53. ‘The right to die with dignity and conscientious objection.’ Colombia’s Constitutional Court, at guaranteeing the fundamental right to live and die with dignity, in the liberating expression of human rights, did not forget the mythical image of Charon ferrying the dead in his boat to Hades. In Colombia, the struggle against death, stubborn and limitless, contrary to the expression of the patients’ will, cannot anymore be accepted as a duty or as a right of the doctors, who now must resign themselves to the conscious and independent decision of their patients, understanding the dimension of existence and of human dignity against the limits of medicine and science, to lead them, just with the necessary palliative care, in crossing the River Styx, to the “world of the dead .” Denying euthanasia, in terms of the decision of the Constitutional Court, constitutes a flagrant violation of the patients’ “life project,” who have, in the established circumstances, the right to legitimate anticipation of death. <http://www.bioline.org.br/request?rc15010>

N.B. English language article. In Greek mythology, Charon is the ferryman of Hades who carries souls of the newly deceased across the rivers Styx and Acheron that divided the world of the living from the world of the dead.

Cont.

- *JOURNAL OF CANADIAN STUDIES*, 2015;48(3):49-78. **'The dilemma of positive rights: Access to health care and the Canadian Charter of Rights & Freedoms.'** An important debate implicating rights and Canadian social policy concerns whether the Charter of Rights & Freedoms should largely be limited to protecting negative rights, which prevent interference from government, or whether it should include positive rights, which require governments to provide entitlements to social services like health care... After examining the Supreme Court of Canada's approach to social rights under the Charter, this essay critically assesses the arguments in favour of expanding constitutional protection for positive rights. Although the essay finds much of the judicial caution regarding positive rights is appropriate, the court's reasoning in several controversial health policy cases is insufficiently attentive to the positive rights implications of its ostensibly negative rights approach. This essay sheds new light on the debate by demonstrating how cases on abortion, supervised drug injection facilities, and assisted suicide present a difficult dilemma from both a policy and rights perspective: courts may rightly avoid creating new social and economic rights, but the rationale they advance in applying negative rights in these cases provides an equally compelling basis for a positive right to access. It is a conundrum both courts and the elected branches of government need to do more to address. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/journal_of_canadian_studies/v048/48.3.macfarlane.html
- *UNIVERSITY OF TORONTO MEDICAL JOURNAL*, 2015;92(3):11-12. **'Rethinking nonmaleficence – harm, the media, and the advocate's obligation.'** The biomedical principle of non-maleficence or "do no harm" has obtained much attention in the context of the Canadian physician assisted suicide (PAS) debate. Borne out of a desire to provide the best care for the patient, the principle practically serves as a safeguard against overtly risky and non-beneficial decision-making practices that may end up causing more harm than good. "Do no harm" (DNH) has been used as an argument against PAS from the perspective of the clinician, but recent Canadian surveys suggest a sizeable swath of the country instead view the forced prolonging of suffering of the terminally ill patient as harmful. If physicians arguing against legislation of PAS believe that death in this case is the real harm, they ought to balance the DNH ethic with the competing biomedical principles as well as the calculus involved in bioethical principlism... Public education and by extension the tone of this debate, could stand to benefit from such explanation. <http://utmj.org/index.php/UTMJ/article/view/1678>

N.B. Click on PDF icon for access to the article.

Worth Repeating

Hope and hopelessness at the end of life

AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY, 2003;11(4):393-405. Efforts to improve end-of-life care have been hindered by widespread delays in discussing and initiating this care. The dynamics of hope and hopelessness may be crucial in these delays. The author reviews recent literature concerning hope and hopelessness at the end of life. Modern dying is more prolonged and more shaped by human choice than ever before. Therefore, hope and hopelessness play a more active role in the dying process. Hopelessness is not a simple product of prognosis, but is shaped by state and trait psychological factors. Hope at the end of life can come in various forms: for cure, for survival, for comfort, for dignity, for intimacy, or for salvation. Hopelessness at the end of life is therefore not simply the absence of hope, but attachment to a form of hope that is lost. The concept of anticipatory grief may help us interpret hope and hopelessness at the end of life. Improving end-of-life care will require looking beyond prognosis and preferences to understand the dynamics of hope and hopelessness. To be successful at diversifying hope at the end of life, we must foster the trusting interpersonal environment where this is possible. [http://www.ajgonline.org/article/S1064-7481\(12\)61295-0/pdf](http://www.ajgonline.org/article/S1064-7481(12)61295-0/pdf)

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/07/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

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>

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