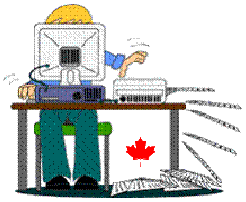
Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice**, **palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry and research.

1 October 2012 Edition | Issue #273



Compiled & Annotated by Barry R. Ashpole

Access to palliative care: Scroll down to Specialist Publications and 'Mapping levels of palliative care development: A global update' (p11), published in *Journal of Pain & Symptom Management.*

Canada

Dying woman outlives her 90 days of home care so Community Care Access Centre cuts her services

ONTARIO | *Toronto Star* – 29 September 2012 – When Doris Landry was discharged from hospital with a life expectancy of one to two months, she entered the 'Home First' program.[1] Offered by the Central Community Care Access Centre, the program provided a caseworker, personal support workers for eight hours every day, and medical equipment including a special bed, an oxygen machine, a wheelchair and a lift, so Landry could live her final days in the comfort of her niece's home. Her niece Charlene Dunlevy took care of her the other 16 hours of the day. "She's good to me," Landry says. The only problem is a bittersweet one: Because Landry survived beyond the program's 90 day funding period, she now faces reductions in care and uncertainty about the medical equipment. http://www.thestar.com/news/gta/article/1264425--dying-woman-outlives-her-90-days-of-home-care-so-ccac-cuts-her-services

[1] Ontario's Aging at Home strategy was launched to expand seniors' access to home care and community support services and create locally driven approaches to enhance seniors' independence and respond to different care needs. http://www.torontocentrallhin.on.ca/Page.aspx?id=5796

Technology can extend lives, but it makes end-of-life decisions trickier

BRITISH COLUMBIA | *The Province* (Vancouver) – 25 September 2012 – With machines now able to keep the critically ill alive forever, the decision of when or where to draw the line becomes a slippery slope: "You put them on machines, then the line where you want to stop becomes much less clear. In some ways, it is better to make that decision before they come to ICU" [says Dr. Najib Ayas, of St. Paul's critical care division]. Yet, few do. With modern-day advances in medicine and technology, death has become something that can be delayed, cheated, beaten, or overcome, at least temporarily. Conversations about death and mortality can be uncomfortable at best, morbid at worst – almost an implicit admission of defeat. But medicine clearly has its limits. http://www.theprovince.com/health/Technology+extend+lives+makes+life+decisions+trickier/7285553/story.html

U.S.A.

Patients afraid to disagree with doctor

CALIFORNIA | *Press-Telegram* (Long Beach) – 26 September 2012 – In the doctor's office ... otherwise confident people frequently become timid. They both respect and fear the physician and have a hard time negotiating treatment options. That's the conclusion from a [recent] study.[1] The researchers recruited 1,340 people between 40 and 60 years old for an online study. The volunteers were presented with a hypothetical scenario in which they were supposed to make a decision about treating a heart condition. In this scenario, as frequently happens in real life, there is no single best treatment based on evidence, so the patient's preferences should be taken into consideration. The investigators found that most of these well-educated study subjects had no problem asking questions or discussing their preferences. A majority of them (70%) said they thought decisions about treatment were best when the doctor and the patient approached them together. When it came to expressing preferences that disagreed with the doctor's recommendation, however, only 14% said they would do so. http://www.presstelegram.com/ci_21637498/joe-and-teresa-graedon-patients-afraid-disagree-doctor

1. 'Communicating with physicians about medical decisions: A reluctance to disagree,' *Archives of Internal Medicine*, published online 9 July 2012 (noted in Media watch, 16 July 2012). http://archinte.jamanetwork.com/article.aspx?articleid=1212630

Family caregiver issues

Family leave: Not a benefit, a protection

WASHINGTON DC | *Washington Post* – 24 September 2012 – A radical, if little noticed, idea came out of the Center for American Progress [CAP] last week.[1] Staff there ran the numbers and found a feasible, relatively painless way to offer U.S. workers paid family leave. Paid family leave is one of those issues that at the moment has plenty of supporters but no political weight. There is yet to be a leader who has proposed a palatable financing structure that would overcome the idea's main opponents. Those would be a business community that fears business owners would bear the brunt of what could be a crippling cost, deficit hawks who view it as a money pit and too many politicians of independent means don't understand why most Americans are crawling to work some days exhausted and overwhelmed. Now, here comes CAP economist Heather Boushey and analyst Sarah Jane Glynn with an idea: Consider paid family leave not a "benefit" but a protection. Their heavily annotated report suggests expanding Social Security to cover family caregiving leave. http://www.washingtonpost.com/blogs/on-parenting/post/family-leave-not-a-benefit-a-protection/2012/09/21/124961b6-041d-11e2-91e7-2962c74e7738_blog.html

1. 'Comprehensive Paid Family and Medical Leave for Today's Families and Workplaces: Crafting a System that Builds on the Experience of Existing Federal and State Programs,' Center for American Progress, August 2012. http://www.americanprogress.org/wp-content/uploads/2012/09/BousheyUniversalFamilyLeavePaper.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW JERSEY | *Star Ledger* (Newark) – 27 September 2012 – **'Controversial bill would allow terminally ill patients to decide when it's time to die.'** A state lawmaker says it's time for New Jersey to openly discuss the most difficult of topics: whether terminally ill patients should be allowed to decide how and when they die. Assemblyman John Burzichelli quietly proposed a bill that would grant doctors the right to prescribe lethal doses of drugs to patients who have less than six months to live. http://www.nj.com/politics/index.ssf/2012/09/controversial_bill_would_allow.html

International

End of life care in the U.K.

Cross party fears that National Health Service reforms risk the right to die at home

U.K. (ENGLAND & WALES) | *The Telegraph* – 30 September 2012 – More than 100 politicians and patients' groups have ... expressed fears that care of the dying will worsen because it does not feature in plans for the restructured NHS. A new NHS [National Health Service] Commissioning Board will supervise 212 groups, led by doctors, who will hold a share of the health budget. Although the system is supposed to devolve power locally, the Government has drawn up a draft "mandate" for the board, which sets out 22 national priorities for the groups – such as making long-term savings and improving patient safety. However, no mention has been made of end-of-life care – nor of current policies which say that services should provide support those who wish to die in their own homes. Research has found that around two thirds of people would prefer to die at home, if they were given the right pain relief and help, yet lack of care means just 21 % deaths occur there. http://www.telegraph.co.uk/health/healthnews/9576296/Cross-party-fears-that-NHS-reforms-risk-the-right-to-die-at-home.html

Of related interest:

- U.K. | Cicely Saunders Institute (King's College, London) – 25 September 2012 – **'Palliative care experts call for better home care.'** A study, carried out by researchers from the Cicely Saunders Institute ... found that 42% of patients with advanced non-malignant conditions reported a preference for home death, yet only 12% of deaths from respiratory and neurological conditions occur at home, and only 6% for dementia. Research ... also found that living alone consistently reduced the chance of home death. Support at home from family carers without professional care made the chance of hospital death three times more likely than when professional carers were also involved. http://www.eurekalert.org/pub_releases/2012-09/kcl-pce092512.php

- U.K. | *Lancashire Telegraph* – 28 September 2012 – **'New 'end of life strategy' drawn up for East Lancashire residents.'** A new strategy is being drawn up after it was revealed more than half of all residents will die in hospital. Despite national and local initiatives across the region to increase choice, in the last year, 54.5% of people died in hospital. There has been a small increase in the number of patients dying at home, but the number of people dying in a hospice has declined. http://www.lancashiretelegraph.co.uk/news/health/9956372.New__end_of_life_strategy__drawn_up_for_East_Lancashire_residents/

Northern Ireland 'end of life care' scheme announced

U.K. (NORTHERN IRELAND) | 4NI News (Belfast) – 27 September 2012 – Health Minister Edwin Poots has revealed an "innovative" new programme intended to improve people's experience of care towards the end of their life. The Palliative and End of Life Care Learning and Development Programme and the Learning Development Programme were announced as he spoke at the launch at the Northern Ireland Hospice. Over £750,000 has been invested in the programme by the Health & Social Care Board, making it the first time a U.K. health authority has invested in a bespoke training and development programme aimed at nurses working in the independent sector. Mr. John Compton, of the Health & Social Care Board, called the programme "essential training and development." "We have 266 registered nursing homes in Northern Ireland with approximately 3-4,000 registered nurses and 9-10,000 health care assistants providing care in this sector. This investment reflects the Commissioners commitment to ensuring all the staff provide care with humanity and compassion, safely and effectively, and to support senior nurses to manage with confidence and respect." http://www.4ni.co.uk/northern_ireland_news.asp?id=151416

Do not resuscitate orders: When hospital CPR should not be used

U.K. | *The Independent* (London) – 24 September 2012 – The issue of resuscitation was recently brought to the fore, following the case of a man with Down's syndrome, who was issued with a Do Not Resuscitate order without consent from either himself or his family. His family is now taking legal action against the hospital on his behalf. The case throws up some interesting questions, particularly the circumstances under which a do not resuscitate decision might be considered. Each year in the U.K., approximately 30,000 patients receive CPR in hospital. The reality of survival rates in today's world is substantially different from early reports with only one to two people surviving for every 10 receiving CPR. Certain factors are known to influence the outcome. For example, a witnessed cardiac arrest, that occurs secondary to an acute cardiac problem, have good outcomes with survival around 40%. By contrast CPR in the very frail, or in patients with an acute stroke, severe injury, severe infection, cancer, liver or renal failure, or homebound lifestyle are associated with poor survival.http://blogs.independent.co.uk/2012/09/24/do-not-resuscitate-orders-when-hospital-cpr-should-not-be-used/

Specialist Publications

Of related interest:

'The problem with actually tattooing DNR across your chest' (p.9), in *Journal of General Internal Medicine.*

Of related interest:

- U.K. | *The Independent* (London) – 1 October 2012 – **'When the doctor changed his mind it felt like a miracle.' A son's quest to stop his father's life support from being turned off has astonished the High Court.** http://www.independent.co.uk/news/uk/home-news/right-to-life-when-the-doctor-changed-his-mind-it-felt-like-a-miracle-8191516.html

Traditional African funerals: A once-beautiful thing

ZAMBIA | *Daily Mail* (Lusaka) – 24 September 2012 – When death knocks on a family's door, the African social fabric comes alive. The church choir brings songs of comfort; relatives prepare meals and accept food and other contributions. Donations help transport mourners from the bus, railway station, or the airport. Young men prepare the fire for the funeral wake outside the home; others work with the family of the deceased on the protocols for the day of the burial. At its core, a traditional African funeral is a beautiful thing. It is supportive, communal, collective, healing, and a shared process of delegated efficiency amongst family, relatives and friends in a place of common purpose. It celebrates the deceased's life, attends to funeral rites, comforts the family – and addresses outstanding family matters. The African funeral used to be rare. When a death occurred, everyone contributed in cash and in kind. Asking for the day off to attend a funeral was an uncommon, and easily granted, request. Today the sheer number of funerals has skyrocketed. HIV and AIDS alone has caused funerals in the hundreds of thousands. http://www.daily-mail.co.zm/?p=15189

Advocating for palliative care for an ageing population: Living to the end

World hospice & palliative care day

October 13 2012

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2012;18(9):420-421.The theme for this year's World Hospice & Palliative Care Day on is 'Palliative care for an ageing population: Living to the end.' Events will be taking place around the world to highlight the rights of older people and the need for better access to quality care and improved quality of life throughout the life course. Working together with healthy-ageing advocates is vital to achieving this vision. http://www.ijpn.co.uk/cgi-bin/go.pl/library/article.html?uid=94350;article=IJPN_18_9_420_421

World Hospice & Palliative Care Day website: http://www.worldday.org/

Assisted (or facilitated) death

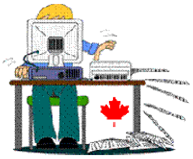
Representative sample of recent news media coverage:

- IRELAND | *The Independent* (Dublin) – 30 September 2012 – **'Courts facing tough task on issue of euthanasia.'** Around the world, judges and lawmakers are dealing with life and death dilemmas posed by incurably ill but competent patients. The Irish courts have already drawn a line in the right-to-die sands. In 1995, the Supreme Court ruled that the right to die included the right to die a dignified and natural death in a case involving a woman who had been in a near-persistent vegetative state for more than 20 years. But the court would not condone any bid to actively bring about a person's death. http://www.independent.ie/opinion/analysis/dearbhail-mc-donald-courts-facing-tough-task-on-issue-of-euthanasia-3243698.html

- INDIA | *Times of India* (Bangalore) – 27 September 2012 – **'72-yr-old's mercy killing plea rejected.'** The high court has rejected the plea of a 72-year-old retired teacher from Davanagere, who sought the court's permission to die. Justice Ajit Gunjal disposed of the petition based on reports by neurosurgical and psychiatric experts from Nimhans [which stated the teacher] does not suffer any pain or severe ailment. Her spine is normal and she can get up without any pain. Neither does she suffer from any mental disorder. http://timesofindia.indiatimes.com/city/bangalore/72-yr-olds-mercy-killing-plea-rejected/articleshow/16566026.cms

- SWITZERLAND | Swiss.ino (Zurich) – 26 September 2012 – **'Swiss parliament rejects tighter controls on assisted suicide.'** Parliament voted against a bid to toughen controls on assisted suicide, rejecting concerns about foreigners travelling to the country to die. Members of the lower house of parliament voted against changing the code, arguing self-regulation by right-to-die organisations such as Exit and Dignitas worked and the liberal rules protected individual freedoms. http://www.swissinfo.ch/eng/news/international/Swiss_parliament_rejects_tighter_controls_on_assisted_suicide.html?cid=33598246

- THE NETHERLANDS | *Dutch News* (Amsterdam) – 25 September 2012 – **'13 psychiatric patients were helped to die last year.'** A total of 13 psychiatric patients were helped to end their life last year, compared with just two in 2010, according to new figures from the regional euthanasia monitoring groups. Euthanasia among people in the early stages of dementia also rose last year to 49 cases, double that of 2010.The figures are in line with a general upward trend. The total number of euthanasia cases rose 18% last year to 3,695 and the number of cases has doubled since 2006, the report said. http://www.dutchnews.nl/news/archives/2012/09/euthanasia_case_rise_steeply.php



Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or 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 courses, and facilitating issue specific workshops, for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://www.ipcrc.net/barry-r-ashpole.php

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

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

Development of the Questionnaire on Palliative Care for Advanced Dementia (qPAD)

AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS | Published online – 20 September 2012 – The qPAD is a two-part instrument that measures long-term care staff knowledge, and beliefs, perceptions, and attitudes about palliative and end-of-life care for persons with advanced dementia. Factor analyses of the Knowledge test ... produced three factors: anticipating needs, preventing negative outcomes, and insight and intuition. Factor analyses of the Attitude Scale ... produced three factors: job satisfaction, perceptions and beliefs, and work setting support of families... These initial findings hold promise for an instrument that measures both knowledge and attitudes of long-term care staff in the care of persons with advanced dementia. http://aja.sagepub.com/content/early/2012/09/14/1533317512459793.abstract

Of related interest:

- *INTERNATIONAL PSYCHOGERIATRICS*, 2012;24(11):1798-1804. **'Preferences for end-of-life treatment: Concordance between older adults with dementia or mild cognitive impairment and their spouses.'** Results of this study show that regarding end-of-life preferences for patients, there is moderate agreement between patients and their spouses, but limited evidence for projection of spouses' preferences on patients (i.e., spouse making a prediction based on own wishes). http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8695335&fulltextType=RA&fileId=S1041610212000877

Medicare as insurance innovator: The case of hospice

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Published online – 25 September 2012 – The stylized fact is that while private insurance has tended to innovate on the benefit design side of the insurance contract, Medicare has lead innovation on the payment side. Traditional or Fee-For-Service Medicare has produced many innovations in the payment for health care services, such as Prospective Payment for hospitals, Diagnostic-Related Groups to categorize care, and the Resource-Based Relative Value System used by the program to pay physicians, while private insurance has produced a series of benefit design innovations. This story misses one important example of Medicare benefit innovation: the creation of the Medicare hospice benefit. http://ajh.sagepub.com/content/early/2012/09/13/1049909112461064.abstract

Concept mapping in palliative medicine research

ANNALS OF PALLIATIVE MEDICINE, 2012;1(2):179-181. Palliative care adopts a share care model that emphasizes the collaboration among patients, families, and health care providers. Different views and different priority of care are often reported. Concept mapping is a research methodology that can best obtain a big picture as well as a clustering of sub-themes that are identified by different parties involved in palliative care. Concept mapping adopts qualitative method to identify themes, and then uses quantitative techniques such as multidimensional scaling to create a map that shows the patterns of relationships between themes. The method draws the shared expertise of a studied group by constructing graphic models of an issue in palliative medicine examined by the group. http://www.amepc.org/apm/article/view/1042/1270

Of related interest:

- *BMC HEALTH SERVICES RESEARCH* | Published online – 27 September 2012 – **'A comparison of strategies to recruit older patients and carers to end-of-life research in primary.'** care.' http://www.biomedcentral.com/content/pdf/1472-6963-12-342.pdf

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Published online – 26 September 2012 – **'Understanding palliative care on the heart failure care team: An innovative research methodology.'** http://www.jpsmjournal.com/article/S0885-3924(12)00354-5/abstract

Why is the Liverpool Care Pathway used for some dying cancer patients and not others? Healthcare professionals' perspectives

BMC RESEARCH NOTES | Published online – 26 September 2012 – This exploratory study has contributed insights into understanding how a small number of doctors and nurses strive to deliver compassionate care to dying patients on busy hospital wards. Whilst recognition of dying for most cancer patients appears to be straight forward there remain a significant number for whom the Pathway is not implemented; this is especially pertinent outside normal working hours. Although the Pathway is advocated as best practice, adopted by organisations and is viewed positively by nurses and junior doctors, this does not guarantee the co-operation of all medical consultants and can lead to professional tension. Despite significant improvements in the confidence of healthcare professionals to deliver effective symptom control at the end of life, attributed to the education and implementation associated with the Pathway, this does not always translate to effective communication about dying, particularly with the patient. Focussed efforts should be directed at education in communication at end of life, addressing priorities of care especially out of hours, ensuring regular senior review of all dying patients and supporting front line staff. http://www.biomedcentral.com/content/pdf/1756-0500-5-524.pdf

Consensus statement: Liverpool Care Pathway for the Dying Patient

U.K. | National Council for Palliative Care – 25 September 2012 – Published misconceptions and often inaccurate information about the Liverpool Care Pathway risk detracting from the substantial benefits it can bring to people who are dying and to their families. In response to this we are publishing this consensus statement to provide clarity about what the Liverpool Care Pathway is – and what it is not. http://www.ncpc.org.uk/sites/default/files/user/LCP%20Consensus%20Statement.pdf

Noted in Media Watch, 30 July 2012:

- U.K. | *Daily Telegraph* – 24 July 2012 – **"Advance refusal' cards for patients fearing 'death pathway."** http://www.telegraph.co.uk/health/elderhealth/9420794/Advance-refusal-cards-for-patients-fearing-death-pathway.html

  N.B. Footnoted in this issue of Media Watch (p.6) is a list of articles on the Liverpool Pathway noted in past issues of the weekly report.

'Who is going to explain it to me so that I understand?' Health care needs and experiences of older patients with advanced heart failure

EUROPEAN JOURNAL OF AGEING | Published online – 22 September 2012 – The main categories derived from patient interviews were: understanding of illness and prognosis, health care services and social life. Patients expressed the need for better information and communication regarding illness and prognosis, and the desire for more respectful treatment by health care providers. Heart failure was not recognized as a potentially life-limiting disease, and the patients had no experience with palliative care services. This study emphasizes the need for improving communication with patients with advanced heart failure. Strengthening the palliative care approach in all relevant services that deliver care for these patients and introducing advanced care planning appear to be promising strategies. http://www.springerlink.com/content/4001j18092105526/

Of related interest:

- *BMJ PALLIATIVE & SUPPORTIVE CARE* | Published online – 27 September 2012 – **"I wish I knew more …' the end-of-life planning and information needs for end-stage fibrotic interstitial lung disease: Views of patients, carers and health professionals.'** No participants [in this study] were aware of any palliative care input, and no participants had considered important end-of-life issues, such as preferred place of care and preferred place of death. http://spcare.bmj.com/content/early/2012/09/27/bmjspcare-2012-000263.abstract

Advance care directives – pending legislation

IRISH MEDICAL NEWS | Published online – 27 September 2012 – It is possible for persons to set out their views regarding future medical care by what are known as advance directives (also known as Living Wills). There is no legislation in relation to advance directives in Ireland and the legal position is quite unclear. An advance directive is basically a document whereby a person sets out the basis on which healthcare decisions should be made if he/she becomes mentally incapable or unable to participate in those decisions. For instance, the document might include the request that certain treatment should not be given in certain situations if the person is not competent to consent to or refuse such treatment at the time. Obviously, an advance directive can only relate to lawful treatment (such as the withdrawal of medical treatment) and cannot relate to unlawful treatment, such as giving a lethal injection with no therapeutic effect and with the intention of terminating life. http://www.imt.ie/opinion/2012/09/advance-care-directives-%E2%80%94-pending-legislation.html

Of related interest:

- *INTERNAL MEDICINE JOURNAL*, 2012;42(9):966-968. **'Should law have a role in end-of-life care?'** Abstract or link to full article unavailable. http://onlinelibrary.wiley.com/doi/10.1111/j.1445-5994.2012.02883.x/abstract

Potentially vulnerable populations

End-of-life care and dying: Issues raised by staff supporting older people with intellectual disability in community living services

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Published online – 21 September 2012 – [Based on the findings of this study] the current status of end-of-life care and dying comprised five key 'issues': knowledge of dying, ethical values, the where of caring, the how of caring, and post-death caring. These issues occurred in relationship with 'partners,' including the dying person, other clients, fellow staff, family, external health services and the coroner. End-of-life care represents a complex interaction between the care issues and the partners involved in care. Despite this complexity, staff were committed to the provision of end-of-life care. http://onlinelibrary.wiley.com/doi/10.1111/jar.12000/abstract

Noted in Media Watch, 24 September 2012:

- *JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Published online – 14 September 2012 – **''If and when?': The beliefs and experiences of community living staff in supporting older people with intellectual disability...'** http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2012.01593.x/abstract?deniedAccessCustomisedMessage=&userIsAuthenticated=false

  N.B. Footnoted in this issue of Media Watch (p.9) is a list of articles on end-of-life care for people with intellectual disabilities that have been noted in past issues of the weekly report.

Supporting rural family palliative caregivers

JOURNAL OF FAMILY NURSING | Published online – 24 September 2012 – In this study, the most prevalent needs identified ... were caring for the patient's pain, fatigue, body, and nourishment, family caregiver [FCG] fatigue and need for respite. Yet few FCGs wanted more attention to these needs by healthcare providers. FCGs resisted considering their own personal needs. Instead, they focused on needs related to providing care including to be (come) a palliative caregiver, be skilled and know more, navigate competing wishes, needs, demands, and priorities, and for "an extra pair of hands." Gaps in rural palliative services contributed to low expectations for assistance; reluctance to seek assistance was influenced by FCGs' resourcefulness and independence. http://jfn.sagepub.com/content/early/2012/09/23/1074840712462065.abstract

The problem with actually tattooing DNR across your chest

JOURNAL OF GENERAL INTERNAL MEDICINE, 2012;27(10):1238-1239. No doubt readers have heard a clinician exclaim, after participating in a code or witnessing the suffering of a resuscitated patient, "I should have DNR tattooed across my chest!" For those individuals who strongly desire not to be resuscitated, the tattoo idea is appealing. By its nature, a tattoo implies a preference against resuscitation so strong that the person has etched the image onto their body. The tattoo is inseparable from the body. Unlike Do Not Resuscitate (DNR) paperwork or medic-alert bracelets, it cannot be misplaced, easily removed, or lost. Emergency responders are unlikely to miss seeing a DNR tattoo on the chest prior to attempting resuscitation. To the extent that we should find ways of respecting persons' deeply held preferences not to be resuscitated, we agree with the sentiment, if not the method. The notion of a tattoo stems in part from fear that such choices will not be respected. http://www.springerlink.com/content/x78847255281h276/fulltext.pdf

Of related interest:

- *JOURNAL OF GENERAL INTERNAL MEDICINE,* 2012;27(10):1383. **'DNR tattoos: A cautionary tale.'** http://www.springerlink.com/content/5j87325767302ht1/fulltext.pdf
- *BMJ QUALITY & SAFETY* | Published online – 11 September 2012 – **'Honouring patient's resuscitation wishes: A multi-phased effort to improve identification and documentation.'** http://qualitysafety.bmj.com/content/early/2012/09/10/bmjqs-2012-000928.abstract?sid=a24f6fa0-3d84-4685-8d4e-30bfd533bc1b

Noted in Media Watch, 5 March 2012:

- U.S. | Associated Press – 27 February 2012 – **'Medical tattoos with vital information replacing bracelets for some.'** http://www.cbsnews.com/8301-504763_162-57386101-10391704/medical-tattoos-with-vital-information-replacing-bracelets-for-some/

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 tool or change document.

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

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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.

A palliative care educational intervention for frontline nursing home staff: The IMPRESS Project

JOURNAL OF GERONTOLOGICAL NURSING | Published online – 17 September 2012 – IMPRESS (IMproving PRofessional Education and Sustaining Support) was a quality improvement EOL care educational intervention (six lectures on core palliative care concepts) for frontline nursing home staff at five community nursing homes. Questionnaires were completed to evaluate frequency of application of palliative care skills before and after the educational series. Nursing home staff reported applying palliative care skills significantly more frequently after the intervention. http://www.healio.com/nursing/journals/JGN/%7B68721BEC-BB03-4074-A9DA-C8B67F3F6A6F%7D/A-Palliative-Care-Educational-Intervention-for-Frontline-Nursing-Home-Staff-The-IMPRESS-Project

Noted in Media Watch, 3 September 2012:

- *COMMUNITY CARE* (U.K.) | Online report – 29 August 2012 – **'How care home staff can gain the end-of-life care skills...'** http://www.communitycare.co.uk/Articles/29/08/2012/118469/how-care-home-staff-can-gain-the-end-of-life-care-skills-they-need.htm

Noted in Media Watch, 7 May 2012:

- *JOURNAL OF PALLIATIVE MEDICINE* | Published online – 2 May 2012 – **'Quality of care and quality of dying in nursing homes...'** http://online.liebertpub.com/doi/abs/10.1089/jpm.2011.0497

Noted in Media Watch, 21 March 2011:

- COCHRANE COLLECTION | Published online – Accessed 18 March 2011 – **'Interventions for improving palliative care for older people living in nursing care homes.'** http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/CD007132/frame.html

End-of-life care from the perspective of primary care providers

JOURNAL OF GENERAL INTERNAL MEDICINE, 2012;27(10):1287-1293. Primary care providers (PCPs) [study participants] wanted to care for their dying patients and felt largely competent to provide end-of-life care. They and their staff reported the presence of five structural factors that influenced their ability to do so: 1) continuity of care to help patients make treatment decisions and plan for the end of life; 2) scheduling flexibility and time with patients to address emergent needs, provide emotional support, and conduct meaningful end-of-life discussions; 3) information-sharing with outside providers and within the primary care practice; 4) coordination of care to address patients' needs quickly; and, 5) authority to act on behalf of their patients. In order to provide end-of-life care, PCPs need structural supports within primary care for continuity of care, flexible scheduling, information-sharing, coordination of primary care, and protection of their authority. http://www.springerlink.com/content/704667603775r717/

Life-sustaining treatment preferences: Matches and mismatches between patients' preferences and clinicians' perceptions

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 26 September 2012 – Clinicians erred more often about patients' wishes when patients did not want treatment than when they wanted it. Treatment decisions based on clinicians' perceptions could result in costly and unwanted treatments. End-of-life care could benefit from increased clinician-patient discussion about end-of-life care, particularly if discussions included patient education about risks of treatment and allowed clinicians to form and maintain accurate impressions of patients' preferences. http://www.jpsmjournal.com/article/S0885-3924(12)00363-6/abstract

Withdrawing artificial nutrition and patients' interests

JOURNAL OF MEDICAL ETHICS | Published online – 25 September 2012 – The author argues that the arguments brought by Counsel for M to the English Court of Protection are morally problematic in prioritising subjective interests that are the result of 'consistent autonomous thought' over subjective interests that are the result of a more limited cognitive perspective. http://jme.bmj.com/content/early/2012/09/24/medethics-2012-100856.abstract

Noted in Media Watch, 23 January 2012:

- *JOURNAL OF MEDICAL ETHICS*, 2012;38(1):64-66. **'Withdrawing and withholding artificial nutrition and hydration from a patient in a minimally conscious state.'** In the summer of 2011 the [U.K.] Court of Protection ruled that it would be unlawful to withdraw artificial nutrition and hydration from a woman, M, who had been in a minimally conscious state for 8 years after contracting viral encephalitis at the age of 43 years. http://jme.bmj.com/content/38/1/64.extract

Family factors affect clinician attitudes in pediatric end-of-life decision making: A randomized vignette study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 26 September 2012 – In this randomized vignette study, the authors have shown that family factors, particularly how involved a family seems to be in a child's life, affect what clinicians think is ethically appropriate in challenging end of life cases. Knowledge of how a family's degree of involvement may affect clinicians should be helpful to the clinical ethics consultants and offer some degree of insight to the clinicians themselves. http://www.jpsmjournal.com/article/S0885-3924(12)00308-9/abstract

Noted in Media Watch, 12 March 2012:

- *PEDIATRICS* | Published online – 5 March 2012 – **'Barriers to conducting advance care discussions for children with life-threatening conditions.'** The top three barriers to advance care discussions were: unrealistic parent expectations, differences between clinician and patient/ parent understanding of prognosis, and lack of parent readiness to have the discussion. http://pediatrics.aappublications.org/content/early/2012/02/29/peds.2011-2695.abstract

Mapping levels of palliative care development: A global update

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Published online – 26 September 2012 –The authors' purpose is to categorize palliative care development, country-by-country, throughout the world, showing changes over time. They adopt a multi-method approach. Development is categorized using a six-part typology: Group 1 (no known hospice-palliative care activity) and Group 2 (capacity-building activity) are the same as developed during a previous study (2006), but Groups 3 and 4 have been subdivided to produce two additional levels of categorization: 3a) Isolated palliative care provision; 3b) Generalized palliative care provision; 4a) Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision; and, 4b) Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. Although more than half of the world's countries have a palliative care service, many countries still have no provision, and major increases are needed before palliative care is generally accessible worldwide.http://www.jpsmjournal.com/article/S0885-3924(12)00334-X/abstract

Extract from *Journal of Pain & Symptom Management* article

In 2011, 136 of the world's 234 countries (58%) had at least one palliative care service – an increase of 21 (+9%) from 2006, with the most significant gains having been made in Africa. Advanced integration of palliative care has been achieved in only 20 countries (8.5%).

Cont.

Noted in Media Watch, 6 February 2012:

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2012;366(3):199-201. **'Painful inequities – palliative care in developing countries.'** http://www.nejm.org/doi/full/10.1056/NEJMp1113622

Noted in Media Watch, 6 June 2012:

- HUMAN RIGHTS WATCH | Published online – 2 June 2011 – **'Global State of Pain Treatment: Access to Medicines & Palliative Care,'** June 2011. http://www.hrw.org/node/98936

Considerations of difference: Is 'complicated grief' a viable new diagnosis in DSM-5?[1]

PSYCHOTHERAPY IN AUSTRALIA, 2012; 18(4):53-54. The process of grief is a normal reaction to the experience of loss of a loved one and should not be pathologised. Mental health professionals working in the area of grief and loss have long agreed that the grieving individual should be allowed to mourn for a period of time, and not be subjected to diagnosis, medicalisation or 'treatment.'http://search.informit.com.au/documentSummary;dn=736644127461028;res=IELHEA

[1] 'Diagnostic & Statistical Manual of Mental Disorders-5' (due to be published in 2013).

Noted in Media Watch, 24 September 2012:

- *OMEGA – JOURNAL OF DEATH & DYING*, 2012;65(4):251-155. **'Complicated grief in the DSM-5'** http://baywood.metapress.com/app/home/contribution.asp?referrer=parent&backto=issue,2,8;journal,1,259;linkingpublicationresults,1:300329,1

  N.B. Footnoted in this issue of Media Watch (p.10) is a list of articles, etc., on complicated grief and the DSM-5 that have been noted in past issues of the weekly report.

Difficult patient loss and physician culture for oncologists grieving patient loss

JOURNAL OF PALLIATIVE MEDICINE | Published online – 27 September 2012 – Oncologists found patient loss particularly difficult for relational reasons including instances where they felt close to patients and their families, when they had a transference to the patient, when patients died young, when they had long-term patients, and when deaths were unexpected. Contextual reasons included when patients and their families were unprepared for death, had unrealistic expectations about cure, when excessive treatments were perceived to be used, when physicians were blamed for the loss, or when families were chaotic or had high needs. Findings further revealed that these losses were occurring within a physician culture that had a stigma around death and dying, viewed emotion as weakness, was focused on cure, and was gendered. http://online.liebertpub.com/doi/abs/10.1089/jpm.2012.0245

Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *PSYCHOLOGY TODAY* | Published online – 26 September 2012 – **'Euthanasia: A good death?'** In a recent case in New Zealand, a man who assisted his wife, Rosie, to die, was discharged without conviction by the court. Rosie was suffering from an aggressive form of multiple sclerosis, with no possibility of remission or reversal, and lived with protracted pain, severe tremors, and was becoming increasingly and rapidly dependent. In her eyes, life was no longer worth living. So she took her life using equipment her husband had, at her request, helped her research and assemble.When she decided the time was right, she asked her husband to leave the house as anyone in the room with her could face more serious criminal charges. http://www.psychologytoday.com/blog/trouble-in-mind/201209/euthanasia-good-death

Worth Repeating

Therapeutic creative writing: A qualitative study of its value to people with cancer cared for in cancer and palliative healthcare

MEDICAL HUMANITIES, 2008;34(1):40-46. This paper reports on a therapeutic creative writing project undertaken at King's College London and University College Hospital London, funded by Arts Council England. The project sought to increase understanding of experiences of personal expressive and explorative writing by cancer patients receiving palliative care. Narrative methods were used to analyse and interpret patients' written and oral (transcripts of semi-structured interviews) responses, researchers' field notes and written responses of staff. These indicated that writing: 1) facilitated patients' ability and opportunity to discover what they thought, felt, remembered; 2) enhanced their awareness of, and ability to express, issues to which focused attention needed to be paid; and, 3) offered satisfaction and fulfilment of creative expression and exploration and the production of writings which to them and close others were vital. Illuminatively drawing upon patients' writings and responses, this paper is underpinned by discussion of therapeutic writing and its relationship to creative writing, with reference to a range of previous research. http://mh.bmj.com/content/34/1/40.abstract?sid=13d455a4-9977-4897-8847-61125fd1e504

Media Watch Online

Canada

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

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

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

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

U.S.A.

Prison Terminal: http://www.prisonterminal.com/news%20media%20watch.html

Europe

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

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

Asia

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://centres.sg/ (Scroll down to 'What's New: Reading List Update')

International

Australasian Palliative International Link: http://www1.petermac.org/apli/links.htm (Scroll down to 'Media Watch')

Palliative Care Network Community: http://www.pcn-e.com/community/pg/file/owner/MediaWatch

International Palliative Care Resource Center: http://www.ipcrc.net/archive-global-palliative-care-news.php

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