

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

Effecting change in the illness experience: Scroll down to [Specialist Publications](#) and 'Intangible values of palliative care' (p.11), in the *European Journal of Palliative Care*.

Canada

It's time to make quality palliative care more accessible

THE CATHOLIC REGISTER | Online – 30 March 2017 – The pledge was buried deep within the federal budget and delivered almost as an afterthought. Still, it is encouraging to see the Liberals keeping a 2015 election promise on palliative care (PC). A year ago PC was totally ignored in the new government's debut budget. It was a notable slight after the Liberals had promised to inject \$3 billion into home and PC over four years. But in a classic example of better late than never, their second budget ... has doubled the total commitment to \$6 billion, but spread it over 10 years. Exactly when those funds will start to flow and how they will be allocated remain unanswered questions. Indeed, the budget signalled no sense of urgency. PC was mentioned briefly on page 158 of a 278-page document in a sentence that said, "Canadians can expect improved access to home, community and PC services." The only other mentions related to a separate \$184-million, five-year investment in home and PC services for First Nations and Inuit. Yet it was a positive week for palliative-care advocates. A day before the budget, a private member's bill on PC moved closer to becoming law when it won unanimous approval from a House of Commons committee. <https://goo.gl/NQX1Vj>

Noted in Media Watch 27 March 2017, #505 (p.1):

- ONTARIO | *The Sarnia Observer* – 22 March 2017 – '**Gladu's private member's bill set for third reading...**' A private member's bill introduced in Parliament by Sarnia-Lambton Conservative MP Marilyn Gladu took another step to becoming a law. A House of Commons committee voted to support the bill providing for development of a national framework for palliative care. <https://goo.gl/eVunV5>
- ONTARIO | My West Nipissing (Sturgeon Falls) – 23 March 2017 – '**Hughes lobbies for better hospice palliative care coverage.**' There's a push in the House of Commons to have the Canada Health Act cover hospice and palliative care. New Democrat Carol Hughes, who represents Algoma-Manitoulin-Kapuskasing, is making the pitch for the wider coverage. <https://goo.gl/sxuDAr>

A chapter in the history of hospice and palliative care in Canada

In March 2001, Liberal Senator Sharon Carstairs was appointed Canada's first Minister with Special Responsibility for Palliative Care ...and in June of the same year the Secretariat on Palliative & End-of-Life Care was established, a first step, working with the provincial and territorial governments, in Health Canada's plan to coordinate the development of a national strategy on palliative and end-of-life care. In March 2007, however, under the Conservative government of Stephen Harper, the Secretariat was disbanded and the work was stopped on the national palliative and end-of-life care strategy. **BRA**

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MACLEAN'S MAGAZINE* | Online – 28 March 2017 – ‘**Canada’s halfway measures on assisted dying fail the mentally ill.**’ The instinct to prioritize extreme physical suffering above all else is a deeply human tendency. Even without first-hand experience, people can relate to tangible pain. Compassion is natural. But abstract torment – the sort of ongoing suffering caused by an unquiet mind – garners far less empathy and even scarcer latitude. However unsettling it is to discuss, it is time for honest, open dialogue to begin on the matter of physician-assisted death for psychological disease. Where the government’s narrow approach to assisted-dying has sown confusion and doubt around patient eligibility and physician liability, the distinct exclusion of psychological suffering further compounds uncertainty, as it inadvertently establishes an hierarchy of disease and opens the extent and validity of another’s suffering to broad debate. When the legitimacy of an illness can be arbitrarily called into question, people living with proven-irremediable torment will be denied their charter right to die simply because their anguish stems from a disrespected diagnosis. <https://goo.gl/1hCtYU>

U.S.A.

Approved Kansas bill: Parent must be told of DNR for child

KANSAS | *The Hutchinson News* – 30 March 2017 – Parents would have to be informed orally and in writing of an intent to institute a do-not-resuscitate order for their minor child, and the order could not be placed if there was a refusal of consent, under a likely new Kansas law. The Kansas House of Representatives voted 121-3 ... for Simon’s Law. The Senate approved it earlier in a 29-9 vote. An attempt to pass a bill of this nature met with easy passage in the Senate last year, but ran out of time for action in the House. The Center for Practical Bioethics in Kansas City, Missouri, said the bill could be better, including language pertaining to conflict resolution, and suggested more discussion before action. <https://goo.gl/73mh9j>

Noted in Media Watch 28 March 2016, #455 (p.3):

- KANSAS | *The Topeka Capital-Journal* – 21 March 2016 – ‘**Senate advances bill on child “do not resuscitate” orders.**’ Health care professionals would be barred from filing “do not resuscitate” orders on patients under 18 years old without parent permission under legislation endorsed by the Kansas Senate. The bill, known as “Simon’s Law,” would prohibit health care professionals from withholding life-sustaining care from patients under 18 without a parent’s consent. <http://goo.gl/CY180b>

Serenity bereavement helps train hospice volunteers in prison

ILLINOIS | *Rochelle News-Leader* (East Rochelle) – 30 March 2017 – Dixon Correctional Center began its prisoner hospice program in 1995 and was one of the first in the nation to offer hospice to their dying inmates. They are currently one of approximately 20 prisons in the nation to offer this service to their inmates. The inmates are chosen through a very rigorous selection process. Up to 50 inmates apply each year to be a hospice volunteer but only 8-9 are chosen. They are then trained through an extensive process that teaches them all aspects of helping someone through their death. Older inmates in Illinois prisons are growing as the total population in prisons rise and as sentences are longer. Also, inmates are now also serving more of their sentences. All of this adds up to more inmates dying in prison from long illnesses. Bereavement coordinator for Serenity Hospice, Cathy Warren, says that the training is very similar to the training she provides to Serenity’s own volunteers. <https://goo.gl/Z5aPAK>

N.B. End-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report is available at: <http://goo.gl/ZpEJyQ>

Why the Centers for Disease Control & Prevention needs to recognize palliative care

PAIN NEWS NETWORK | Online – 28 March 2017 – A little over a year ago, the Centers for Disease Control & Prevention (CDC) released its ‘Guideline for Prescribing Opioids for Chronic Pain.’¹ Its goal is to help reduce the raging and heartbreaking overdose epidemic in the U.S. Unexpectedly, the guideline has exposed the extraordinary need for palliative care (PC) for millions of patients who may live for decades with intractable pain. These patients now face enormous obstacles getting medically-needed opioids for effective pain control, especially when the dose exceeds the highest recommendation made in the guideline of 90 morphine milligram equivalents per day. This unbending recommendation is too low to provide pain control that will keep many intractable pain patients out of agony. In the last year, untold numbers of chronic pain patients requiring PC lost the correct opioid dose for their diseases – making work, self-care, and family interactions harder or impossible. <https://goo.gl/wXLIZq>

Need for a palliative care appendix to the ‘Guideline for Prescribing Opioids in Chronic Pain’

The CDC should produce an appendix for all prescribers – not just primary care doctors – that would help them provide fully adequate pain relief to palliative care (PC) patients with life-long pain rather than near-death pain. The appendix could start by examining the legislative or regulatory language used in the 13 states that define intractable pain and that allow higher than typical opioid dosing. The appendix also needs to emphasize research on the most painful long term diseases, which will offer physicians a wider variety and more specialized array of treatment options than is available from a focus on generalized chronic pain. The appendix could begin with the recognition that intractable pain patients needing PC do not get “high” or “euphoric.” Opioids are medicines that reduce pain and let them live closer to normal lives.

1. ‘Guideline for Prescribing Opioids for Chronic Pain – U.S., 2016,’ *Morbidity & Mortality Weekly Report*, Centers for Disease Control & Prevention, March 2016. [Noted in Media Watch 21 March 2016, #454 (p.3)] <http://goo.gl/Ng6PZ5>

Noted in Media Watch 20 March 2017, #504 (p.14):

- *REHABILITATION ONCOLOGY* | Online – 27 February 2017 – ‘**Opioid campaigns’ impact on advanced cancer and hospice and palliative care.**’ Recent national opioid campaigns may have significant, unintentional, and adverse consequences on the medical management of patients with advanced cancers or those receiving hospice and palliative care. New guidelines are likely to impose even tighter controls on opioids, further reducing accessibility to these drugs. <https://goo.gl/Qw3dYU>

“Pre-hospice” saves money by keeping people at home near the end of life

KAISER HEALTH NEWS | Online – 27 March 2017 – Most aging people would choose to stay home in their last years of life. But for many, it doesn’t work out: They go in and out of hospitals, getting treated for flare-ups of various chronic illnesses. It’s a massive problem that costs the health care system billions of dollars and has galvanized health providers, hospital administrators and policymakers to search for solutions. The importance of programs like Transitions is likely to grow in coming years as 10,000 baby boomers – many with multiple chronic diseases – turn 65 every day. Transitions was among the first of its kind, but several such programs, formally known as home-based palliative care (PC), have since opened around the country. They are part of a broader push to improve people’s health and reduce spending through better coordination of care and more treatment outside hospital walls. But a huge barrier stands in the way of pre-hospice programs: There is no clear way to pay for them. <https://goo.gl/1QAdCg>

Related

- CALIFORNIA | Jefferson Public Radio (Redding) – 16 July 2014 – ‘**Coordinated care for those nearing life’s end – but does it save money?**’ Federal lawmakers are taking up issues around end-of-life care. They’re investing money into programs that care for the nation’s sickest patients in a new way. One could be a model for the rest of the country. The Advanced Illness Management program is not hospice. This program is for the pre-hospice population, people estimated to be in the last 18 months of life. <https://goo.gl/aC5XsR>

A new frontier in health care fraud: Hospice care

LEXOLOGY | Online – 27 March 2017 – In 2014, an estimated 1.6 to 1.7 million patients received services from a hospice provider. The Medicare hospice benefit is the predominate source of payment for that care. According to a study by the National Hospice & Palliative Care Organization, the percentage of hospice patients covered by the Medicare hospice benefit versus other payment sources was 85.5% in 2014. Given that the Medicare reimbursements for hospice care ranges from about \$150 per day for routine hospice services up to over \$800 per day for continuous care, the costs to the Medicare program for hospice are now upwards of \$15 billion per year. Unfortunately, the vital and necessary end-of-life services provided by hospice programs are now yielding an increasing number of fraud, waste, and abuse cases. In 2015, the federal government prosecuted over 60 cases of fraud related to hospice providers with a cost to the Medicare program of hundreds of millions of dollars. Based on recent hospice fraud, waste, and abuse cases, the types of illegal schemes seen in the hospice care industry fall into several broad categories: 1) Kickbacks paid to physicians and other healthcare providers for hospice referrals; 2) “Recruiting” hospice patients who are not medically eligible for hospice care; 3) ,Classifying patients as requiring a higher level of care than medically necessary; and 4) Providing more treatment than medically necessary. Examples of these schemes abound. <https://goo.gl/UMOzqw>

Noted in Media Watch 19 September 2016, #480 (pp.1-2):

- *THE WASHINGTON POST* | Online – 15 September 2016 – ‘How tens of thousands of patients who weren’t actually dying wound up on hospice care.’ A 2014 *Washington Post* investigation found, the number of patients who outlived hospice care in the U.S. has risen dramatically,¹ in part because hospice companies earn more by recruiting patients who aren’t actually dying. Now government inspectors have turned up information about how that happens. About one in three hospice patients were not given key information about what the choice of hospice entails at the time they enrolled according to a report being released by the Office of Inspector General of the Department of Health & Human Services.² <https://goo.gl/CaZqkT>

1. ‘The business of dying,’ *The Washington Post* [The 7-part series was noted in Media Watch through 2014] The series can be downloaded at: <http://goo.gl/FrTz89>
2. ‘Medicaid Fraud Control Units Fiscal Year 2015 Annual Report,’ Office of Inspector General, Department of Health & Human Services, September 2016. <https://goo.gl/3pdBoH>

N.B. Additional articles on Medicare fraud in the U.S. in the context of hospice care are noted in this issue of Media Watch.

Are right-to-try laws a last hope for dying patients – or a false hope?

THE WASHINGTON TIMES | Online – 26 March 2017 – Thirty-three states have passed such laws, which ostensibly allow patients to take experimental medicines outside of clinical trials and without Federal Drug Administration (FDA) oversight as long as the therapies have undergone preliminary safety testing. Many of the remaining states are considering such bills or are expected to do so. And now, for the first time, federal legislation is gaining traction. The anti-regulatory mood dominating Washington is boosting these efforts. But the increased momentum is raising alarms, with opponents saying that such laws largely offer false hope. That’s because many drug companies are reluctant to provide medications outside of clinical trials – and why critics insist that the FDA is not the problem. In 2016, they note, the agency revamped its “expanded access” program to speed unapproved drugs to patients who have no alternatives and can’t get into clinical trials. The FDA approves almost all such requests, the data shows. The notion that the FDA would be barred from considering all data has consumer advocates, ethicists and drug-safety experts in an uproar. If a person is harmed by an experimental drug, they say, that has implications for anybody who might eventually take the medicine. <https://goo.gl/SzY1UK>

N.B. Additional articles on “right-to-try” laws are noted in Media Watch 6 March 2017, #502 (p.6).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **MULTIPLE SCLEROSIS NEWS TODAY** | Online – 21 March 2017 – **‘Physician assisted suicide’s appeal to MS patients in unbearable pain highlights urgency in treating depression.’** Half of the more than 7,500 multiple sclerosis (MS) patients responding to a survey revealed they’d consider physician-assisted suicide if they could no longer enjoy anything that made life worth living.¹ Considering that depression goes hand in hand with MS, the findings underscore the importance of a vigilant, pro-active approach to diagnosing and treating depression among MS patients. The authors emphasized that those who responded to their survey did not represent the entire MS community, indicating that numbers might have looked different if a larger proportion of younger, non-white people had participated. The survey ... asked participants to consider five theoretical situations, and rate whether they definitely would consider, probably would consider, probably would not consider, or definitely would not consider physician-assisted suicide in each situation. <https://goo.gl/8xnJbZ>

Specialist Publications

‘Multiple sclerosis and suicide’ (p.16), in *Multiple Sclerosis Journal*.



Multiple sclerosis by the numbers: Facts, statistics. Source: Healthline <https://goo.gl/nPyBBI>

1. ‘High hypothetical interest in physician-assisted death in multiple sclerosis,’ *Neurology*, published online 15 March 2017. <https://goo.gl/Hyw3p0>

Noted in Media Watch 17 August 2017, #423 (p.17):

- **OMEGA – JOURNAL OF DEATH & DYING** | Online – 13 August 2015 – **‘Patients feeling severely affected by multiple sclerosis: Addressing death and dying.’** 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. <https://goo.gl/fI5KER>



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://goo.gl/5CHoAG>

International

End-of-life care in New Zealand

Government looks to prioritise palliative care

NEW ZEALAND | News Talk ZB (Auckland) – 30 March 2017 – The Government's making assurances palliative care (PC) is one of its health priorities. It comes as a review of the sector recommends major changes and improvements because of a rising demand for PC from the country's aging population. 'The Adult Palliative Care Services in New Zealand: Review and Action Plan' shows there will be an over 50% increase in the number of people needing PC over the next 20 years.¹ It's recommending greater emphasis be put on PC, its quality be improved, that the capability of informal carers be increased, and that response to those with PC needs be improved. In Budget 2015 the Government invested \$76.1 million into hospice services. That included \$24.1 million to support the delivery of new PC services in aged residential care, primary care and other community settings. <https://goo.gl/Ql1Vr1>

1. 'The Adult Palliative Care Services in New Zealand: Review and Action Plan,' Ministry of Health, Government of New Zealand, March 2017. <https://goo.gl/PT64BW>

Noted in Media Watch 5 December 2016, #490 (p.12):

- **PROGRESS IN PALLIATIVE CARE** | Online – 1 December 2016 – '**The status of a public health approach to palliative care at New Zealand hospices.**' Analysis of the quantitative results [of this mixed method study] confirmed that a public health approach to palliative care (PC) was a current priority at 60% of New Zealand hospices. However, both phases of the study demonstrated that community engagement, one of the chief out-workings of a public health approach to PC, was incompletely understood and practised. <https://goo.gl/DCcXTI>

Noted in Media Watch 12 September 2016, #479 (p.5):

- NEW ZEALAND | *The Dominion Post* (Wellington) – 7 September 2016 – '**Hospice proposal illustrates failure to plan for palliative care.**' The volume of palliative care (PC) that aged care facilities are now required to provide has led to some labelling members of the New Zealand Aged Care Association as *de facto* hospices, but without the resourcing or the recognition. This is largely due to policy failing to keep up with the changing nature of aged care. Rest homes aren't seen as providers of PC, but the reality is soon most of us will die in one. <http://goo.gl/z6Z65X>

End-of-life care in Thailand

Dignified to the end

THAILAND | *The Bangkok Post* – 26 March 2017 – The National Health Act of 2007 is the first law that recognises the living will, allowing patients' wishes to be honoured. But the delay put Thailand in the 3A category for palliative care,¹ which means that while we have the law, the system has yet to be implemented. The result is that only some major hospitals in Thailand recognise and honour this law. Patients with terminal illnesses are turned away from hospitals simply because the doctors can't heal them. The limited number of beds and high medical fees are other key factors that force such patients to resort to home care with no professional training or lack of knowledge in healthcare. The National Cancer Control Programme for 2013-2017 specifically mentions preparation for death, the living will and a good death. However, its main focus is on patients with cancer, although the number one cause of



Cont.

death among Thais is heart-related problems, which account for 39% of the total, while cancer represents 36%. The programme mainly focuses on cancer patients because doctors perceive that patients with other diseases still have a fighting chance – unlike cancer, especially when it is discovered at the final stage of life for patients with terminal illnesses. <https://goo.gl/rtolbh>

1. Development of palliative care (PC) is categorized using a six-part typology, i.e., Group 1 (no known hospice-PC activity) and Group 2 (capacity-building activity). Groups 3 and 4 are sub-divided: 3a) Isolated PC provision; 3b) Generalized PC provision; 4a) Countries where hospice-PC services are at a stage of preliminary integration into mainstream service provision; and, 4b) Countries where hospice-PC services are at a stage of advanced integration into mainstream service provision.

Noted in Media Watch 27 June 2016, #46 (p.4):

- THAILAND | *The Bangkok Post* – 22 June 2016 – ‘**Terminally ill need home-based care.**’ In Thailand, we mostly take care of terminally ill patients with what is called “sustaining” care in hospitals. In fact, most of these patients would prefer to stay at home where things are familiar rather than in a hospital. But Thailand does not have the necessary conditions in place, apart from some informal arrangements, to make this possible. <http://goo.gl/NIHmYk>

N.B. Thailand was ranked 44th of the 80 countries surveyed in the ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. Commissioned by The Lien Foundation of Singapore. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

Ireland’s Health Service Executive is to spend up to €500,000 hiring experts to bring about “culture change” in ailing health service

IRELAND | *The Irish Sun* (Dublin) – 25 March 2017 – The company [i.e., successful bidder] will be needed for three years, according to the Health Service Executive, with an option of an additional 12 months. A tender, lodged by the health body, says “external expertise in behaviour-based culture change is required.” The aim is to “develop and roll out a social movement in the health services to make the values of care, compassion, trust and learning more visible.” Clearly, in the areas of palliative care, for instance, there needs to be an institutionalised form of understanding of families who are under pressure. <https://goo.gl/70R0cJ>

Specialist Publications

‘Care home trains staff to help “understand life at sea”’ (p.15), in *Nursing Times*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | Dutch News – 30 March 2017 – ‘**Dutch doctors reject separate euthanasia rules for “completed lives.”**’ The Dutch doctors association, Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst, is not in favour of drawing up specific euthanasia rules for elderly people who consider their lives have been completed. Although the wish of some people who are not physically ill to die is palpable, new legislation aimed specifically at such cases would be “undesirable,” the association said in a statement. <https://goo.gl/OWjpVG>

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Specialist Publications

Compassion fatigue among palliative care clinicians: Findings on personality factors and years of service

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 March 2017 – Palliative medicine is a rewarding field, but providers encounter patient trauma on a routine basis. Compassion fatigue, marked by burnout, secondary traumatic stress, and low satisfaction may result. However, professionals differ markedly in how they respond to patient trauma. The objective of the current study was to determine whether personality traits of neuroticism and agreeableness relate to aspects of compassion fatigue, after accounting for time spent working in the field. Providers [i.e., study participants] who had worked longer reported higher levels of satisfaction and lower levels of burnout. Neuroticism demonstrated strong significant associations with secondary traumatic stress and burnout. Agreeableness was significantly and strongly associated with compassion satisfaction. These associations held after accounting for years spent working in the field. <https://goo.gl/n62JxS>

Noted in Media Watch 13 February 2017, #499 (p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 February 2017 – ‘**Addressing palliative care clinician burnout in organizations: A workforce necessity, an ethical imperative.**’ Efforts to mitigate and prevent burnout currently focus on individual clinicians. However, analysis of the problem of burnout should be expanded to include both individual- and systems-level factors as well as solutions; comprehensive interventions must address both. <https://goo.gl/q2l0Te>

N.B. Additional articles on clinician burnout in the context of hospice and palliative care are noted in Media Watch 23 January 2017, #496 (p.11).

Palliative care nursing for patients with neurological diseases: What makes the difference?

BRITISH JOURNAL OF NURSING | Online – 27 March 2017 – Neurodegenerative diseases progress slowly, creating increasing physical disability with unpredictable disease trajectories. The disease's life-threatening nature often places these patients in palliative care (PC). There are several factors that complicate the care of patients with neurodegenerative diseases in PC units. Owing to physical impairments, there are many communication barriers between patients and staff. Nurses are not able to duplicate the patient's meticulous daily routine leading to caregiver mistrust in the nurse's competencies. Even if the patient is hospitalised, caregivers may not take the much-needed time off to recuperate. The placement of patients with neurodegenerative diseases in PC is confusing, since they rarely die during in-hospital treatment, but might even get better due to multidisciplinary treatment. Finally, patients and caregivers lack adequate knowledge about disease progression and available help and support programmes. Patients with neurodegenerative diseases urgently need PC and nurses and caregivers need better preparation to appropriately deal with these diseases. <https://goo.gl/5q0ngV>

Related

- *FORTSCHRITTE DER NEUROLOGIE PSYCHIATRIE*, 2017;85(03):146-155. ‘**Therapeutic decisions concerning severe neurological diseases and at the end of life.**’ This article first describes the basis for each medical action, i.e., ethical aspects, medical indication and patient agreement. Then the different ways to find out the patient's wishes depending on his ability to agree as well as the possibilities for advance directives (including advance care planning) and health care proxies are discussed. Suggestions for adequate documentation are given. In parallel, the relevant legal paragraphs and statements of the German medical association are presented. <https://goo.gl/Sk6ZOr>

N.B. German language article.

Cont.

Noted in Media Watch 3 October 2016 #482 (p.9):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):232-235. '**Palliative care in chronic and progressive neurological disease: Summary of a consensus review.**' In collaboration with the European Academy of Neurology, a taskforce of the European Association for Palliative Care has produced a consensus review on the development of palliative care (PC) for people with chronic and progressive neurological disease. It makes recommendations on the early integration of PC, multidisciplinary team care, communication, symptom management, carer support, end-of-life care – including the wish for hastened death – and training and education of professionals.

N.B. Access to this article requires a subscription to the journal. Contents page: <https://goo.gl/IUscng>

Noted in Media Watch 20 June 2016, #467 (p.14):

- *NEUROLOGICAL SCIENCES* | Online – 14 June 2016 – '**Need for palliative care for neurological diseases.**' The realization of an effective palliative approach to neurological diseases requires specific skills and expertise to adapt the concept of palliation to the peculiarities of these diseases; this approach should be realized through the cooperation of different services and the action of a multidisciplinary team in which the neurologist should play a central role to identify and face the patient's needs. <http://goo.gl/kOQ9z7>

End-of-life care in England

Identifying patients' priorities and preferences at the end of life

BRITISH MEDICAL JOURNAL | Online – 28 March 2017 – Patients approaching the end of life are not always recognised as such by their GP surgeries. In north east Essex, a survey showed only 35% of patients who died were on a palliative care register and only 20% had their choice of where to die documented. Even where wishes were known, they were not shared, says Karen Chumbley, clinical director of St. Helena Hospice in Colchester who was appointed in 2015 after more than a decade as a GP. The plan for improvement was based around a register, 'My Care Choices,' and a hospice advice and support line, 'Singlepoint,' which is available 24/7 ... for anyone believed to be in the last year of their life. Primary care was commissioned to identify people, and the hospital, mental health trust, and care homes were engaged to make sure that as many patients as possible were included. "Deaths in hospital, which were above the east of England average at 49%, have fallen to 43%, representing more than 220 deaths a year," Chumbley says. "A third of people who died in the area last year had their choices recorded, and three quarters of those who have recorded choices die in their place of choice. Over 6,000 have used the register since it started. "We'd like to do more. Academic papers say that 70% of deaths are predictable, but unless there's a huge change in national culture I don't think we'll ever capture more than 50%. The practice where I worked tried really hard, and got 50 to 60%. That may be the best we can hope for." <https://goo.gl/3HJhDf>



N.B. The 'My Care Choices' initiative described in this article is one of several "finalists" in the hospice and palliative care category of the upcoming 2017 *British Medical Journal Awards*. Other finalists in this category include initiatives by Cornwall Hospice Care, cross-setting consistent anticipatory prescribing guidance; the Velindre (Cardiff) National Health Trust (NHS), looking for a way of better explaining to patients what CPR is; and, the University Hospitals Bristol NHS Foundation Trust's poor prognosis letter project.
BRA



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

“Nowhere else will take him”: Palliative care and homelessness



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(2):54. Recognition of the inadequacies of current systems calls for a different approach to palliative care for people who are homeless. We

know that prognostication is difficult in any population, but for people who are homeless, challenges are amplified by uncertainty, complexity, vulnerability and often substance misuse, which at present appear to close doors to traditional services. Parallel planning could be explored as a way of working with these complexities. For the delivery of compassionate care at the end of life (EoL), there is a need for the promotion of multidisciplinary in-reach into hostels and the provision of a specialised facility, supported by health, social and housing services, that understands the needs of homeless people. This could offer short-term respite care and also be a place where someone could potentially die. An example of this is already in place in Canada. By addressing this inequity we have the opportunity to promote dignity and choice at the EoL for a population that have rarely had either.

Noted in Media Watch 23 January 2017, #496 (p.7):

- *BULLETIN OF EUROPEAN HEALTH PSYCHOLOGY SOCIETY*, 2016;Suppl. ‘**Challenges and recommendations in increasing homeless persons' access to palliative care: An international systematic review.**’ The U.K. Department of Health strives to provide palliative care at the time of need for everyone, regardless of “wherever the person may be,” “irrespective of social economic deprivation.” This goal has not been reached for homeless people who face numerous multifaceted challenges, including accessing health care. <https://goo.gl/9ecWXy>

N.B. Additional articles on end-of-life care for the homeless are noted in past issues of Media Watch, e.g., 13 March 2017, #503 (p.6); 17 December 2017, #495 (p.1); 5 December 2016, #490 (p.6); 8 August 2016, #474 (p.12); and, 14 March 2016, #453 (pp.14-15).

Capacity and palliative care: Helping patients implement estate planning



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(2):58-63. It is never too late for a patient to make or change a valid will, even while they are actively dying, provided that they have the necessary capacity to do so. Supporting patients in this regard, by contemporaneously assessing and meticulously documenting their capacity, is an important component of holistic palliative care (PC). The clinical method described in this article is universally applicable to all PC settings, but – as with all clinical guidelines – it should be tailored to each patient’s individual circumstances. While the Banks vs good fellow criteria represent the basis for internationally accepted legal tests for testamentary capacity, variations exist in some jurisdictions. If in doubt, request an explanation of the legal test relevant to your jurisdiction from the instructing solicitor.

N.B. The common law test for testamentary capacity in England has been long established, being set out in the case of *Banks v Goodfellow* (1869).



Randomised controlled trials involving people nearing death: Proposed solutions to ethical challenges



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(2):65-67. Randomised controlled trials (RCTs) are the gold standard research design for evaluating efficacy because they minimise bias and the effects of confounding variables. Therefore, they provide high-quality evidence and accurate information that can be helpful in guiding professionals in their attempts to apply the principles of beneficence and non-maleficence to autonomous decisions; they also aid in applying the principle of justice in resource allocation when considering treatment for patients. However, gathering evidence through RCTs that involve people nearing death is ethically challenging.

Related

- *THE PATIENT* | Online – 31 March 2017 – ‘**Speaking up: How patient and physician voices shaped a trial to improve goals-of-care discussions.**’ Stakeholder input informed the development of a novel intervention that physicians seemed to find both valuable and in sync with their needs and their practice schedules. Where communication about difficult subjects and shared decision making are involved, including multiple stakeholder groups in study design, implementation, and outcomes measurement may have far-reaching effects. <https://goo.gl/dDibpU>

Psychological ideas in palliative care: Emotional regulation



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(2):68-71. We all have the capacity to experience emotions, which are a complex mix of thoughts, physical symptoms, expressions and behaviours. We are not born with the skills to regulate our emotions; we have to learn them as part of our emotional and social development. Most of us have a relatively broad repertoire of effective emotional regulation skills we can draw on when feelings run high, but for a minority of people this is not the case. By understanding how our patients typically regulate emotions, we can adapt their care environment and our own responses to support them to do so...

Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 30 March 2017 – ‘**Dyadic psychological intervention for patients with cancer and caregivers in home-based specialized palliative care...**’ Few home-based specialized palliative care (SPC) interventions systematically integrate psychological support. The authors present a psychological intervention for patient-caregiver dyads developed for an ongoing randomized controlled trial of home-based SPC... <https://goo.gl/3NoXkm>

Noted in Media Watch 27 February 2017, #501 (p.7):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2017;24(1):24-27. ‘**Psychological ideas in palliative care: Attachment theory.**’ Not every patient needs, wants or has access to formal contact with a psychologist. What’s more, all members of a multidisciplinary team are likely to experience the impact of psychological matters on their daily practice with patients and colleagues, whether or not their role is to explicitly address those.

N.B. Additional articles on the psychosocial care and the role of clinical psychologists in palliative care are noted in Media Watch 20 March 2017, #504 (pp.10-11).

Intangible values of palliative care



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(2):72-74. Intangible values within palliative care (PC) include both the nature of the illness as a lived experience and the essence of caring and medicine. The PC we provide is based on intangible values, which, despite being non-material, can be expressed through words and actions. Patients and their families perceive and appreciate the values of PC; they feel cared for and accompanied during the dying process. The difficulty in transmitting the message of PC lies precisely in the intangible nature of what we wish to transmit. Studying the most hidden and intangible part of our role can help us to value and understand PC.

Death and the Maiden: How women deal with grief



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(2):76-81. Addressing the specific needs of female grief is important for several reasons. Women experiencing grief significantly outnumber men, as a direct result of women's higher life expectancy and a more pronounced tendency to commit to a relationship with an older partner. Bereaved women are at higher risk of mental and physical illness compared with the general married population. The widely-held view that women fare better in the grieving process is questionable and lacks scientific evidence. Taken together, these factors advocate for a more differentiated view on the distinctive features of female grief, which is lacking as, de facto, little research has paid attention to the impact of gender on responses to bereavement.

Related

- *BEHAVIORAL SCIENCES* | Online – 25 March 2017 – '**Death of an ex-spouse: Lessons in family communication about disenfranchised grief.**' The death of a loved one is an emotional-laden experience, and while grief and mourning rituals are less formal today in many communities, there remain some social norms for individuals to process loss. The death of an ex-family member, such as a former spouse, is more complicated and expectations for how to respond are fraught with uncertainty. This article explores the concept of disenfranchised grief, which is "grief that is experienced when loss cannot be openly acknowledged, socially sanctioned, or publicly mourned" through the author's experience of the death of her ex-husband. <https://goo.gl/iRvEhW>
- *PSYCHO-ONCOLOGY* | Online – 28 March 2017 – '**Pre-loss grief in family caregivers during end-of-life cancer care: A nationwide population-based cohort study.**' Severe grief symptoms in family caregivers during end-of-life (EoL) cancer trajectories are associated with complicated grief and depression after the loss. Nevertheless, severe grief symptoms during EoL caregiving in caregivers to cancer patients have been scarcely studied. In this population-based prospective study of 3,635 caregivers to 9,512 patients severe pre-loss grief symptoms were significantly associated with distress, low preparedness, and little communication during caregiving. <https://goo.gl/x9jJqM>

Home care services for sick children: Healthcare professionals' conceptions of challenges and facilitators

JOURNAL OF CLINICAL NURSING | Online – 23 March 2017 – Three categories emerged [in this study]: 1) A challenging opportunity; 2) A child perspective; and, 3) Re-organise in accordance with new prerequisites. Providing home care services for children was conceived to evoke both professional and personal challenges such as feelings of inadequacy and fear, and professional growth such as increased competence and satisfaction. Conceptions of whether the home or the hospital was the best place for care differed. Adapting to the child's care was conceived as important. Cooperation with paediatric departments and a well-functioning team work were important organisational aspects. <https://goo.gl/CZPyjm>

Noted in Media Watch 7 March 2017, #452 (p.11):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 29 February 2016 – '**Evaluating a pilot paediatric hospice-at-home service: A literature review.**' This literature review aims to offer practitioners an overview of the key components involved in designing the evaluation of a paediatric hospice-at-home pilot that will assess the effectiveness, efficiency and sustainability of the programme. <http://goo.gl/5oJYKy>

Noted in Media Watch 5 October 2015, #430 (pp.11-12):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 29 September 2015 – '**Community palliative care nurses' challenges and coping strategies on delivering home-based pediatric palliative care: A qualitative study.**' The results of this study reinforces the need for integration of pediatric palliative care teaching and communication skills training into all undergraduate health care programs. <http://goo.gl/v44oB9>

Clarifying values and preferences for care near the end of life: The role of a new lay workforce

JOURNAL OF COMMUNITY HEALTH | Online – 28 March 2017 – The authors report how trained community health workers (CHWs) used Go Wish (GW) cards to identify patients' highest priority preferences and evaluated whether engaging in advance care planning (ACP) conversations was associated with subsequent health care utilization. A one-year long, pre-post longitudinal design was used to evaluate an educational intervention using mixed-methods. 392 patients (mean of 73.3 years, 82% women, 48% African American, 43% Caucasian) enrolled in the Aging Brain Care program and participated in ACP discussions with CHWs. Eighty-six patients' data indicated that they had engaged in a preferences-for-care process using GWR cards. The top-three card choices by patients was attending to spirituality and religious concerns, preparing for end of life, and maintaining personal wholeness. <https://goo.gl/oQVQIJ>

Communication about dying, death, and bereavement: A systematic review of children's literature

JOURNAL OF PALLIATIVE MEDICINE | Online – 27 March 2017 – Children's books have the potential to facilitate communication about death for children living with a serious illness and for children coping with the death of a loved one. Two-hundred-ten books met inclusion criteria. The dying subject was primarily a grandparent or pet. Books on the experience of a child dying were scarce. The word death or dying was used in 75% of the books, while others utilized euphemisms. The majority of books featured animals or Caucasian subjects and included spiritual elements such as heaven. Less than one-quarter of the books included tools for readers to address the topic of death. Storybooks can be a helpful tool to introduce communication about dying and death with children. Gaps exist in current children's literature to effectively enable children to reflect on their own dying process. A general summary of available books is provided to assist those caring for children and families facing end-of-life issues. <https://goo.gl/rsmWWo>

Noted in Media Watch 28 October 2013, #329 (p.7):

- *EDUCATION & SOCIETY*, 2013;31(1):37-52. 'An analysis of books for preschool children experiencing bereavement and loss.' To enhance a child's ability to cope after the loss of a loved one, parents and caregivers may use children's books as one of a variety of available strategies. When using this familiar form of therapy with pre-schoolers, it is important to choose books that are developmentally appropriate for the child and the situation at hand. <https://goo.gl/aDU6En>

Palliative care in surgery: Defining the research priorities

JOURNAL OF PALLIATIVE MEDICINE | Online – 24 March 2017 – Given the acute and often life-limiting nature of surgical illness, as well as the potential for treatment to induce further suffering, surgical patients have considerable palliative care (PC) needs. Yet, these patients are less likely to receive PC than their medical counterparts and PC consultations often occur when death is imminent, reflecting poor quality end-of-life care. Surgical patients would likely benefit from early PC delivered alongside surgical treatment to promote goal-concordant decision making and to improve patients' physical, emotional, social, and spiritual well-being and quality of life. To date, evidence to support the role of PC in surgical practice is sparse and PC research in surgery is encumbered by methodological challenges and entrenched cultural norms that impede appropriate provision of PC. The objective of this article is to describe the existing science of PC in surgery within three priority areas and expose specific gaps within the field. The authors propose a research agenda to address these gaps and provide a road map for future investigation. <https://goo.gl/RGRopi>

Noted in Media Watch 16 May 2017, #462 (p.7):

- *ANNALS OF SURGERY* | Online – 9 May 2016 – 'Palliative care and surgical training: Are we being trained to be unprepared?' The current system for educating surgical trainees enjoys well-deserved acclaim for producing thoughtful and technically skilled individuals, but continues to inadequately prepare and train young surgeons to care for seriously ill and dying patients. Accordingly, a dramatic change to structure palliative and end-of-life care into surgical training and the willingness of practicing surgeons to actively participate in this care are essential <http://goo.gl/YjIC36>

Cont.

Noted in Media Watch 30 November 2015, #438 (p.9):

- *JAMA SURGERY* | Online – 25 November 2015 – ‘**Palliative care interventions for surgical patients: A systematic review.**’ Despite the growth in attention to palliative care (PC), evidence substantiating its usefulness in surgery is sparse. Although most studies reported positive findings, the evidence was inconsistent, and many studies were small and did not measure the outcomes they intended to achieve, such as goal-concordant care. In the absence of data from high-quality research, the role of PC in improving surgical practice remains poorly defined. <https://goo.gl/dWcBE5>

Rethinking functionality and emotions in the service consumption process: The case of funeral services

JOURNAL OF SERVICES MARKETING, 2017;31(3). The study shows that compared to other traditional services, funeral services are characterized by their strong emotiveness, non-recurrence, irreversibility, uncommonness, high level of symbolism and personalization and emotion control of the service provider. The study also argues that funeral services quality is strongly dependent on funeral houses’ integrated logistics, proximity and integrity. Because of consumers’ lack of competency, funeral companies need to guide and educate consumers about the criteria they should use to evaluate the service quality. Because funeral consumers are strongly emotion-driven at the purchase time, funeral services providers should find the right balance of emotions to express. <https://goo.gl/TJr44P>

Noted in Media Watch 18 July 2016, #471 (p.13):

- *MORTALITY* | Online – 5 July 2016 – ‘**Bodies and ceremonies: Is the U.K. funeral industry still fit for purpose?**’ The U.K. funeral industry’s structure revolves around those who manage the body rather than the ceremony. This structure, in which the client contracts with a funeral director who sub-contracts the funeral ceremony to a priest or celebrant, was fit for purpose in the nineteenth century when most of the family’s choices concerned hardware (coffins, carriages, horses, etc.) for the body’s containment and transport. <http://goo.gl/40nQBA>

Using action learning sets to support change in end-of-life care

LEADERSHIP IN HEALTH SERVICES, 2017;30(2). The educational intervention described in this paper is delivered by specialist palliative care (PC) practitioners to those working with dying patients and their families in non-specialist settings. The programme consists of two components: the first taught/ experience based component takes place in a hospice. The second integral component involves action learning sets which are facilitated by specialist PC staff over a six month period. Action learning sets provide support which enables staff to implement changes to end-of-life care. Participants ... were motivated to change practice and identified themselves as change agents. Management support was vital to allow participants the authority to implement changes to practice. <https://goo.gl/Xu64x1>

An increasing problem in publication ethics: Publication bias and editors’ role in avoiding it

MEDICINE, HEALTH CARE & PHILOSOPHY | Online – 25 March 2017 – Publication bias distorts the accumulated data in the literature, causes the over estimation of potential benefits of intervention and mangles the risks and adverse effects, and creates a barrier to assessing the clinical utility of drugs as well as evaluating the long-term safety of medical interventions. The World Medical Association, the International Committee of Medical Journals, and the Committee on Publication Ethics have conferred responsibilities and ethical obligations to editors concerning the avoidance of publication bias. Despite the explicit statements in these international documents, the editors’ role in and ability to avoid publication bias is still being discussed. Unquestionably, all parties involved in clinical research have the ultimate responsibility to sustain the research integrity and validity of accumulated general knowledge. Cooperation and commitment is required at every step of a clinical trial. However, this holistic approach does not exclude effective measures to be taken at the editors’ level. The editors of major medical journals concluded one precaution editors can take is to mandate registration of all clinical trials in a public repository as a precondition to submitting manuscripts to journals. <https://goo.gl/m0fU3u>

Trans-Atlantic death methods: Disciplinarity shared and challenged by a common language

MORTALITY | Online – 21 March 2017 – The different countries that death and dying researchers reside within often shape not only research agendas but also research methodologies. The U.K. and the U.S. are two examples of countries that share a common language and intellectual history, but their discourses on death have been very different. These differences are partly explained through cultural practices, and also government funding of research, definitions of death and end-of-life planning education. The authors argue that early death scholarship in the U.S. impacted death research and outcomes in both the US and the U.K., but that recent scholarship in both countries has caused the two countries to diverge in two major areas: 1) The methodological approaches to death studies; and, 2) The educational training of medical and hospice personnel in direct contact with the dying. The authors argue that in order for death studies to fully benefit from trans-Atlantic dialogue on death, both countries need to move towards a more integrated trans-disciplinary model. <https://goo.gl/cdMzc8>

Care home trains staff to help “understand life at sea”

NURSING TIMES | Online – 29 March 2017 – A care home for former sailors has launched an innovative training scheme to help staff better understand the life experiences of their residents and enable them to tailor care provision. The programme has been introduced at Belvedere House in Surrey [England]), which is run by the Royal Alfred Seafarers’ Society. It aims to help staff deal with residents’ more challenging behaviour and understand the reasons and causes behind the more complex behavioural manifestations some of the most vulnerable, former seafaring residents present. The charity noted that some of the many difficulties experienced during a career at sea, such as cramped and sparse accommodation, extensive separation from families, and often harsh working conditions, were known to potentially lead to both physical and psychological problems in retirement. Through the targeted training, staff experienced first-hand the living conditions aboard ships, and gained an understanding of residents’ reactions and behaviour that may have been affected by their careers and living conditions at sea. <https://goo.gl/cZGESH>

Palliative and end-of-life care in the masters of social work curriculum

PALLIATIVE & SUPPORTIVE CARE | Online – 30 March 2017 – There is a shortage of social workers who have PC expertise. The aging U.S. population and advances in extending life for seriously ill persons require social workers in a wide range of health care and other settings with specialized PC expertise, as well as those with basic competence in PC. The objective of the present study was to document course content on palliative care in Masters in Social Work (MSW) programs in the U.S. and Canada. A cross-sectional design with an online questionnaire was used. All 248 accredited MSW programs in the U.S. and 32 programs in Canada were invited to participate. The measures included the characteristics of the courses on PC. Of the 105 participating programs, only 10 had courses dedicated to PC, 9 of which were part of a specialization/certificate program. Few programs had plans to develop a dedicated course. There were 106 courses in 63 MSW programs with some content on PC. The majority of these had, and few had at least 50%, of PC content. <https://goo.gl/NQX1Vj>

Noted in Media Watch 1 August 2016, #473 (p.14):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2016;12(3):185-194. ‘**A time and place: The role of social workers in improving end-of-life care.**’ With the release of a second Institute of Medicine report devoted to what it means to die in America in the 21st century,¹ momentum and opportunity for change may increase. If this is to happen, social workers will need to deliver the range of bio-psychosocial care that patients and families so desperately need. However, holistic care of the individual will only improve if the nation also addresses ongoing systemic problems in financing, policy, and service delivery in end-of-life care.. <http://goo.gl/2hrcbo>

1. ‘Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,’ Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://goo.gl/mm4o6W>

What's dignity got to do with it? Patient experience of the Dignity Care Intervention: A qualitative evaluation study

SAGE OPEN NURSING | Online – 22 March 2017 – The findings of this study provide evidence that the Dignity Care Intervention (DCI) allows patients to convey diverse dignity-related needs to community nurses (CNs). As a key component of the DCI, use of the Patient Dignity Inventory facilitated patients' communication of their dignity-related needs to their CNs. Patients expressed increased satisfaction with the support they received. The DCI is particularly useful in helping CNs to deliver psychosocial care, previously identified as a difficult area for CNs in practice. The use of care pathways detailing interventions to manage clinical problems and ensure systematic integration of the best available evidence into care delivery can improve end-of-life care. <https://goo.gl/KFUF6w>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MULTIPLE SCLEROSIS JOURNAL* | Online – 22 March 2017 – '**Multiple sclerosis and suicide.**' Mortality rates are elevated in people with multiple sclerosis (MS) relative to the general population. Epidemiological data suggest that the standardized mortality ratio for suicide in MS is approximately twice that of the general population with younger males in the first few years following diagnosis most at risk. Rates of suicidal intent, a potential harbinger of more self-destructive behavior, are also elevated, but the frequency with which intent is followed by suicide is not known. Depression, severity of depression, social isolation, and alcohol abuse are associated with thoughts of suicide. While vigilance on the part of clinicians is required, particularly in the context of high-risk patients, it is also recognized that prevention is dependent on full disclosure of intent. <https://goo.gl/RQtpfv>

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, research and teaching tool.

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Something Missed or Overlooked?

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

Worth Repeating

“Yes it’s sad, but what should I do?”: Moving from empathy to action in discussing goals of care

JOURNAL OF PALLIATIVE MEDICINE | Online – 17 December 2013 – The communication skills of noticing emotional cues and responding empathically are necessary but insufficient for some conversations about redefining goals of care. For some patients, an empathic response by a clinician is insufficient to move the conversation forward. The authors describe an expert approach that links empathy to action. In this approach, they outline: 1) How affect provides a spotlight that illuminates what is important; 2) How empathy affords a way to connect with patients and families that engages deep values; 3) How clinicians can infer deep values through an associative process with patients; and, 4) How clinicians can then design actions with patients and families and nurture their commitment to the actions. [Noted in Media Watch 23 December 2013, #337 (p.14)] <https://goo.gl/OA9rL4>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/dxmEdJ>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to ‘Aggregators’ and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

Barry R. Ashpole
Guelph, Ontario CANADA

‘phone: 519.837.8936
e-mail: barryashpole@bell.net