# 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

The family system and family communications in end-of-life care: Scroll down to <u>Specialist Publications</u> and 'Validation of a model of family caregiver communication types and related caregiver outcomes' (p.16), in *Palliative & Supportive Care*.

# **Canada**

#### Canadian Partnership Against Cancer

### More is not always better in cancer care: Partnership report

THE WINDSOR STAR | Online - 31 March 2016 - A new report ... looking into whether Canadian patients receive appropriate cancer care shows ... patients undergo an estimated 770,000 interventions each year that may be of low value or expose them to unnecessary harm.1 "More is not always better when it comes to cancer care." said Dr. Geoff Porter, a surgical oncologist and Expert Lead in Clinical Care at the Partnership. "Providing patients with high-value care means ensuring they receive tests and treatments that offer the greatest clinical benefit with the most efficient use of resources. This can help improve quality of care and the sustainability of the health care system." The report measures how current oncology practices compare to cancer-related recommendations established by Choosing Wisely Canada - a campaign that aims to help physicians and patients engage in conversations

about potentially unnecessary tests, treatments and procedures. The report establishes baseline data for Choosing Wisely Canada's cancerrelated recommendations. http://goo.gl/1VulYF

# Extracts from the Canadian Partnership Against Cancer report

Approximately 9,000 cancer patients near the end of life were admitted to an ICU, a setting that is not optimal for addressing the palliative care needs of patients at the end of life.

An effective, person-centred focus on palliative care can help patients with the treatment decision making process, increasing the use of services that offer the most benefit to patients and improving quality of life.

1. 'Quality & Sustainability in Cancer Control: A System Performance Spotlight Report,' Canadian Partnership Against Cancer, March 2016. <a href="http://goo.gl/oG6JWO">http://goo.gl/oG6JWO</a>

Noted in Media Watch, 25 May 2015, #411 (p.11):

JOURNAL OF ONCOLOGY PRACTICE, 2015;11(3):e296-e303. 'Choosing Wisely Canada cancer list: Ten low-value or harmful practices that should be avoided in cancer care.' Choosing Wisely Canada, modeled after Choosing Wisely in the U.S., is intended to identify low-value or potentially harmful practices relevant to the Canadian health care environment <a href="http://goo.gl/lZSPxu">http://goo.gl/lZSPxu</a>

## Rural areas challenging for right to die access

BRITISH COLUMBIA | The Citizen (Prince George) - 28 March 2016 - Accessing the right to die looks very different in a rural setting. As the federal government grapples with a legislative framework for physician-assisted suicide ... policy makers must account for the realities of its more remote settings." One of the issues is that the rural perspective and the rural resources can be very different than what people in the big cities take for granted," said Catharine Schiller, a lawyer, nurse and assistant professor in University of Northern British Columbia's School of Nursing. Schiller recalled watching a recent interview that discussed an ideal setting where a family doctor who understood the intricacies of a person's medical past and overall health would help the person make an informed decision (and only if they fit the parameters laid out in Carter v. Canada Supreme Court decision that a person must be "suffering intolerably as a result of a grievous and irremediable medical condition.") "All I could think of was, that sounds so much like a big city perspective because when you talk to somebody who's in northern British Columbia where we have a shortage of family physicians, you're unlikely to have had a family physician for years and years and years," she said. In many

cases, it isn't doctors who are the primary medical providers in these areas, she said, and the Carter decision didn't address caregivers like nurse practitioners. <a href="http://goo.gl/gtqQwT">http://goo.gl/gtqQwT</a>

## **Specialist Publications**

'Geographic variation of inpatient care costs at the end of life' (p.12), in Age & Aging.

'Supporting generalist nurses in the rural setting with the introduction of a clinical assessment process' (p.12), in *International Journal of Palliative Nursing*.



'End-of-life care in rural communities.' http://goo.gl/WPJvBI

'National palliative medicine survey looks at urban versus rural.' http://goo.gl/GEJL4u

Noted in Media Watch, 7 March 2016, #452 (p.12):

PALLIATIVE MEDICINE | Online – 4 March 2016 – 'Place of death in rural palliative care: A systematic review.' There have been many studies on the actual and preferred place of care and death of palliative patients; however, most have been whole population surveys and/or urban focused. Data and preferences for terminally ill rural patients and their unofficial carers have not been systematically described. http://goo.gl/PYW3KX

**N.B.** Selected articles on end-of-life care in rural communities are noted in the issues of Media Watch of 8 February 2016, #448 (p.9); 4 January 2016, #443 (p.9); 30 November 2015, #438 (p.12); 14 September 2015, #427 (p.8); 7 September 2015, #426 (p.17); 17 August 2015, #423 (p.14), 11 May 2015, #409 (p.13), and 30 June 2014, #364 (p.15).



Media Watch: Back Issues

Available on the International Palliative Care Resource Center website: http://goo.gl/frPgZ5

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NATIONAL POST | Online 1 April 2016 'Majority rejects assisted suicide for mentally ill, poll finds.' A majority of Canadians believes psychological suffering on its own should never be grounds for granting a doctor-assisted death. While Canadians seem particularly appalled by the idea of allowing assisted suicide for "mature minors" with psychological suffering, a majority supports lethal prescriptions for terminally ill children and youth, a newly released poll suggests. <a href="http://goo.gl/keRfgi">http://goo.gl/keRfgi</a>
- ALBERTA | The Gateway (University of Alberta) 30 March 20916 'Registered nurses can't legally advise on assisted death.' RNs need a defined role throughout the entire process of physician-assisted death we have valuable assessment skills and interview skills to complement the physicians, and the gift of time spent with patients that simply does not occur in the MD role. We may be the ones to notice that a patient doubts their decision, or the first health care professional approached with a request for more information regarding assisted death. https://goo.gl/4c5TcX
- CBC NEWS | Online 28 March 2016 'Physician-assisted dying: A Jewish community perspective.' Physician-assisted dying remains a deeply personal and contentious issue among Jewish Canadians. Some in our community support physician-assisted dying, focusing on the plight of those stricken by a terminal or debilitating illness with no possibility of pain relief. Others oppose physician-assisted dying based on traditional religious grounds or due to concerns about a knock-on effect toward more broadly applied euthanasia. <a href="http://goo.gl/JA6SKR">http://goo.gl/JA6SKR</a>
- ONTARIO | The Sault Star (Sault Ste. Marie) 27 March 2016 '10% of doctors polled would "consider" providing service.' An anonymous survey conducted during a recent meeting of Sault Area Hospital (SAH) physicians indicated 10% of those polled would "consider" participating directly, and most were warm to the issue "The vast majority of physicians recognized that they would refer their patients if necessary," Dr. Heather O'Brien, SAH chief of staff, told the Sault Star... "And a small minority of physicians would be willing to participate in end-of-life (procedures) in the setting of legislation being aligned and clear guidelines and training (developed)." <a href="https://goo.gl/BPbvQP">https://goo.gl/BPbvQP</a>

## U.S.A.

## Medicare is often overbilled by hospices, and pays twice for some drugs

THE NEW YORK TIMES | Online - 2 April 2016 Hospices often bill Medicare for a higher level of care than patients need, and Medicare often pays twice for the prescription drugs provided to people who are terminally ill, federal investigators say in a new report. The extra cost to Medicare was put at more than \$260 million a year. "Many hospices have been billing far more than they should have," said Nancy T. Harrison, a deputy regional inspector general at the Department of Health & Human Services who led the investigation. The investigators found that Medicare was paying hospices almost four times as much as it should have for some patients. The patients were receiving "inpatient care" when all they needed was less-expensive routine care in their homes, the report said. Medicare now pays hospices an all-inclusive rate of \$720 a day for inpatient care and no more than \$187 a day for routine home care. Most hospice care is provided to Medicare beneficiaries in their homes. But if their pain or symptoms become too difficult to manage at home, they can be admitted to a hospital, nursing home or hospice inpatient unit. http://goo.gl/3dd3Qh

## Specialist Publications

'Culturally competent palliative and hospice care training for ethnically diverse staff in long-term care facilities' (p.9), in American Journal of Hospice & Palliative Medicine.

'Hearing loss in hospice and palliative care: A national survey of providers' (p.13), in *Journal of Pain & Symptom Management*.

1. 'Hospices Inappropriately Billed Medicare Over \$250 Million for General Inpatient Care,' Office of Inspector General, March 2016. <a href="http://goo.gl/vIIOp6">http://goo.gl/vIIOp6</a>

#### **Choosing Wisely Campaign**

# Why we need to be aware of the "therapeutic illusion"

MINNESOTA | The Minneapolis Post - 31 March 2016 - One of the most stubborn obstacles to reducing unnecessary - and sometimes harmful - medical tests and treatments is a psychological phenomenon known as the "illusion of control," argues a provocative commentary... In the commentary, Dr. David Casarett, a professor of medicine at the University of Pennsylvania, describes how the illusion of control - which in medicine is sometimes called the "therapeutic illusion" - leads physicians to believe that their efforts and medical tools (tests, drugs, procedures) are more effective than they actually are. Of course, it's an illusion that patients have as well, in large part because of the human tendency to confuse correlation and causation. "The outcome of virtually all medical decisions is at least partly outside the physician's control, and random chance can encourage physicians to embrace mistaken beliefs about causality," writes Casarett. Another well-known psychological phenomenon – confirmation bias – reinforces therapeutic illusion, he adds. Once a treatment is under way, physicians (and patients) tend to look for evidence that it is having some kind of positive effect. https://goo.gl/RsXG9E

#### Extract from New England Journal of Medicine article

Choosing Wisely may be an ambitious attempt to address the problem of overtreatment, but it's not realistic to think that any single solution will be effective. The campaign's reliance on medical societies risks a certain parochial defensiveness, which has produced recommendations focused disproportionately on other specialties' procedures. A more comprehensive, broad-based approach could begin with education that provides trainees with the skills to recognize and manage the therapeutic illusion.

1. 'The science of choosing wisely – overcoming the therapeutic illusion,' *New England Journal of Medicine*, 374(13):1203-1205 http://goo.gl/j37hGT

Noted in Media Watch, 2 March 2015, #399 (p.8):

■ JAMA INTERNAL MEDICINE | Online – 25 February 2015 – 'Challenges in Choosing Wisely's international future.' Since its 2012 launch by the American Board of Internal Medicine Foundation, the Choosing Wisely campaign has affected more than 60 U.S. specialty societies. The campaign is becoming an international phenomenon. This rapid expansion is a heartening sign that there is increasing international sentiment against wasteful medical practices. <a href="http://goo.gl/tpc6Ql">http://goo.gl/tpc6Ql</a>

## Confusion on palliative care vs. hospice limits help at end-of-life

LOUISIANA | The Louisiana Weekly (New Orleans) - 29 March 2016 - Multiple studies show that, compared to awareness of hospice, "There's significantly less familiarity with palliative care (PC)," said Lyle Fettig, MD, director of Indiana University School of Medicine's Hospice & Palliative Medicine Fellowship program centered in Indianapolis. PC is now a recognized medical subspecialty, but experts in the field say lack of knowledge about it within the general public, and even among medical providers, is impeding the many benefits of these services for those who most need them. PC, according to the New York-based Center to Advance Palliative Care, is appropriate for individuals of any age and at any stage of a serious illness, whether it is cancer or a chronic condition, such as heart or lung disease. The goal is to improve quality of life for both patient and family through a holistic, interdisciplinary team approach. PC addresses symptom control of a medical condition, as well as side effects of treatment. Families may be connected to community services, financial resources, and help for caregivers. Hospice includes palliative or comfort care to relieve pain and other symptoms but, generally speaking, it is for individuals anticipated to have six months or fewer to live and who are no longer receiving active treatment. "The reason that people get PC confused with hospice is that PC can be introduced earlier on," said Kathryn Felts, a PC and hospice nurse practitioner with Parkview Home Health % Hospice. Patients in PC services can still be receiving curative treatment. Patients access PC most often at a hospital or it is at least initiated there, but they can also have it provided on an outpatient basis, if it's available. http://goo.gl/6gWPHJ

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

CALIFORNIA | The Los Angeles Times (OpEd) – 27 March 2016 – 'Who will exercise the right to die?' As California's End of Life Option Act takes effect in June, data from states where aid in dying is already legal raises a question: Who will use the new law? In Oregon, Washington, Montana and Vermont, experience shows that participants will be few in number, well less than 1% of those who die each year. We also know, based on 18 years of data from Oregon ... that most of them will be older, white and well-educated. That puts to rest the worries many have had – that masses of people, particularly the disadvantaged, will be targeted and coerced into dying if physicians are allowed to prescribe a lethal dose of medicine for terminal patients. But in a diverse state like California, the data highlight another concern: The right to die may not be readily available to many and even most people. The modern aid in dying movement developed alongside medical advancements in the 1960s and '70s – CPR, respirators and defibrillators – that made it possible to save lives that otherwise would have been lost. But those advances also posed new challenges for end-of-life decision making. At the same time, some terminally ill patients found that "doing everything" to live put the emphasis in the wrong place: length of life over quality of life. http://goo.gl/oXkDVM

# **International**

#### End-of-life care in England

# End-of-life care in National Health Service still not good enough, report finds

U.K. (England) | The Guardian - 31 March 2016 - National Health Service (NHS) care of people dving in hospital is much better care since the Liverpool Care Pathway (LCP) was axed, but too many are still not receiving proper palliative care (PC) in their final hours, a new report has found. Those who die overnight or at the weekend may be denied the right care because only 11% of hospital trusts in England provide specialist palliative services around the clock, according to a detailed audit of end-of-life care. It found that "a broad front of improvements in nearly all aspects of care of the dying in hospitals" occurred between 2013, when the controversial LCP was scrapped, and 2015. Its findings are based on an analysis of the care of 9,302 patients who died in hospital in England in May 2015. Dr. Adrian Tookman, a clinical director at the charity Marie Curie, which co-funded the research with NHS England, said that "there has been a real effort to improve care of the dying in hospital over recent years." For example, staff had discussed the patient's impending death with their relatives in 95% of cases. And in 54% of cases people close to the patient had had the chance to say what help and support they

needed, almost double the 25% who had that opportunity when the audit was first undertaken in 2013.<sup>2</sup> However, Tookman added: "We can't ignore the fact that the vast majority of dying people and those close to them still have limited or no access to specialist PC support when they need it in hospital. This is not right, not good enough." <a href="http://goo.gl/YR2DQ0">http://goo.gl/YR2DQ0</a>

#### Quote from The Guardian report

Care of the dying has no respect for time. Round-theclock availability of specialist palliative care in hospitals should be the norm. When this care is missing, people suffer, and this suffering can live long in the memory of those they leave behind.

# **Specialist Publications**

'Nurse-led end of life care in London is helping people have more control over their last days' (p.15) in *Nursing Standard*.

- 'End of Life Care Audit Dying in Hospital: National report for England 2016,' Royal College of Physicians, March 2016. <a href="https://goo.gl/YILmtu">https://goo.gl/YILmtu</a>
- 'National Care of the Dying Audit of Hospitals,' May 2014. [Noted in Media Watch, 19 May 2014, #358 (p.3)] <a href="http://goo.gl/p1C0NB">http://goo.gl/p1C0NB</a>

## Beijing promotes eco-friendly burials ahead of Tomb-Sweeping Day

CHINA | *The China Daily USA* (New York) – 28 March 2016 – With Qingming Festival, or Tomb Sweeping Day, around the corner, Beijing issues new regulations to encourage eco-friendly burials. No more traditional tombs will be built in public cemeteries and the lease of existent ones will not to be renewed, according to the regulations issued by Beijing Civil Affairs Bureau. Also, the use of non-decomposable construction materials, such as cement and stone, should be reduced in building tombs while degradable urns are encouraged in funerals. Chinese tradition holds that the dead should be buried, but the custom has put a strain on the populous country's land resources and pushed up the price of cemetery plots. To deal with the problem, Beijing started promoting eco-friendly burials in the 1990s, encouraging land-saving funerals such as sea burials and tree funerals. As a result, ecological burials have gained popularity among Beijing residents in recent years: eco-friendly burials accounted for some 46% of all funerals last year, in which the number of sea burials increased from 307 in 2009 to around 2,000 last year. http://goo.gl/5vmezU

Noted in Media Watch, 17 March 2014, 349 (p.4):

CHINA | China News Service (Beijing) – 11 March 2014 – 'More sea burials planned to meet rising demand.' Sea burials have been around in Shanghai since 1991; the events are considered solemn affairs that merit proper arrangements and ceremony. The two ferries used by the Funeral Services Center at the Shanghai Civil Affairs Bureau carry up to 250 people per trip. Each funeral group can comprise up to six relatives, so the voyages generally involve upward of 40 burials. Once the ashes have been scattered, families return to Binhaiguyuan Cemetery where the names of their late loved ones are carved onto a memorial. The idea of the eco-friendly service was introduced to Shanghai in response to dwindling supplies of land for traditional burials in the city. http://goo.gl/LIVuOT

#### Paediatric palliative care in Spain

## Unanimous support for the creation of palliative care units

SPAIN | Sur in English.com (Málaga) – 28 March 2016 – The Andalusian parliament has unanimously approved a motion that will see, with immediate effect, the creation of a network of paediatric palliative care (PC) services in both community hospitals and at home. The initiative has also been signed by other [political] parties with parliamentary representation. The parliament urges the Junta (the regional authority) to ensure the continuity of paediatric hospice care "for 24 hours a day, 365 days a year," including home care. It is estimated that 80% of children die in their own homes. The network will work with district and city hospitals and will be launched in two phases, the first of which within

three months. In the first phase, two children's PC units will be created, one in Seville and the other in Malaga; and, in the second phase new specific units will be established in other provinces. http://goo.gl/CPgu3x

## **Specialist Publications**

'Early introduction of palliative care and advanced care planning for children with complex chronic medical conditions: A pilot study' (p.9), in *Child: Care, Health & Development.* 

# 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

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

### Exploring nurse communication about spirituality

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 31 March 2016 – Although spiritual care is considered one of the pillars of palliative care, many health-care providers never receive formal training on how to communicate about spirituality with patients and families. Nurses reported that communication about spirituality was primarily initiated by patients, rather than family members, and spiritual topics commonly emerged during the end of life or when patients experienced spiritual distress. Nurses' experiences highlighted the positive impact spiritual conversations had on the quality of patient care and its benefit to families. Spiritual communication was described as an important nursing role at the end of patients' lives, and non-verbal communication, listening, and discussing patients' emotions were emphasized as important and effective nurse communication skills during spiritual care conversations. It is evident that patients want to discuss spiritual topics during care. Study findings illustrate the need to develop a spiritual communication curriculum and provide spiritual care communication training to clinicians. http://goo.gl/txrLyu

#### Related

- PALLIATIVE MEDICINE, 2016;30(4):325-326. 'What is the point of spirituality?' Two papers in this issue look at spirituality: Best et al on the challenge it presents to contemporary medicine and Vermandere et al on a method for taking a spiritual history.<sup>1,2</sup> Both hold the general view that spirituality is an important component of a person's engagement with illness, but neither defines exactly what is being examined. Prima facie this is odd, which raises questions about whether spirituality is conceptually different to psychology or a philosophy of life, whether it has utility in medicine and whether the lack of an agreed definition matters. http://goo.gl/9BRfNR
  - 'Doctors discussing religion and spirituality: A systematic literature review,' Palliative Medicine, 12 August 2015. [Noted in Media Watch, 17 August 2015, #423 (p.18)] <a href="http://goo.gl/UYijGQ">http://goo.gl/UYijGQ</a>
  - 'Spiritual history taking in palliative home care: A cluster randomized controlled trial,' Palliative Medicine, 16 September 2015. [Noted in Media Watch, 21 September 2015, #428 (p.14)] <a href="http://goo.gl/IEV8Qq">http://goo.gl/IEV8Qq</a>
- REVISTA BIOÉTICA (Conselho Federal de Medicina, Brazil), 2016;24(1):165-175. 'Palliative care, spirituality and narrative bioethics in a Specialized Health Care Unit.' This article presents the results of a study of the narratives of six people directly involved in the routine of the palliative care (PC) unit at the Hospital de Apoio de Brasilia, with the aim of contributing to the study of the complex problems faced by PC in daily practice. Focusing on the relationship between spirituality and bioethics, interviews with professionals, patients and families were conducted, seeking answers to the question of the meaning of life and its relationship to suffering. <a href="http://goo.gl/BIXTGG">http://goo.gl/BIXTGG</a>
  - N.B. English language article.

Noted in Media Watch, 7 March 2016, #452 (p.13):

POSTGRADUATE MEDICAL JOURNAL | Online – 1 March 2016 – 'Culture and spirituality: Essential components of palliative care.' Research evidence shows the importance of identifying and addressing cultural and spiritual aspects of care held by patients, families and staff. These are often neglected in clinical practice due to the focus on biomedical concerns and staff discomfort in engaging with beliefs and culture. <a href="http://goo.gl/9rCTUe">http://goo.gl/9rCTUe</a>

**N.B.** Selected articles on spirituality in the context of end-of-life care are noted in Media Watch of 8 June 2015, #413 (pp.10-11).

# Caring About Residents' Experiences & Symptoms (CARES) Program: A model of palliative care consultation in the nursing home

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 31 March 2016 – In this study, 170 nursing home residents were seen by the CARES Program between February 2013 to December 2015, 48% for skilled services, and 52% for long term care. The majority of referrals were for goals of care and concurrent symptom management. Following consultation, 67% of residents had a change in code status. Of residents desiring a palliative course 90% were never hospitalized. Overall, 53% of residents died; and those in long term care dying more often with hospice. The model has potential to be reproducible in in other communities. <a href="http://goo.gl/9cirRm">http://goo.gl/9cirRm</a>

#### Related

GERIATRICS & GERONTOLOGY INTERNATIONAL (Japan Geriatrics Society), 2016;16(Suppl1):132-139. 'Reconsidering long-term care in the end-of-life context in Japan.' The authors propose expanding the scope of long-term care such that it involves caring for dying individuals; that is, end-of-life care. In doing so, they identify challenges that families and care/medical professionals face in attempts to design and provide end-of-life care under Japan's societal contexts. http://goo.gl/HkFJXI

## Decision-making of patients with implantable cardioverterdefibrillators at end of life: Family members' experiences

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 31 March 2016 – Many patients with advanced heart failure (HF) experience the life-extending benefits of implantable cardioverter-defibrillators (ICD), but at the end stage of HF patients may experience shocks with increasing frequency and change the plan for end-of-life (EOL) care, including the deactivation of the ICD. Understanding the decision-making of patients with ICD at EOL can promote informed decision-making and improve quality of EOL care. http://goo.gl/IQL83m

Noted in Media Watch, 1 February 2016, #447 (p.11):

- EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING (European Society of Cardiology), 2016;15(1):8-9. 'Magical thinking around end of life: An editorial on 'Implantable cardioverter defibrillator deactivation discussions reality vs. recommendations.' Discussing deactivation with a patient is difficult and requires skill and empathy. The ability to hold these conversations is not innate, but requires training and practice. <a href="http://goo.gl/SmlFdi">http://goo.gl/SmlFdi</a>
  - 'Implantable cardioverter defibrillator deactivation discussions: Reality vs. recommendations,' European Journal of Cardiovascular Nursing (Preventive Cardiovascular Nurses Association), 2016;15(1): 20-29. [Noted in Media Watch, 4 May 2015, #408 (p.10)] <a href="https://goo.gl/vli8KR">https://goo.gl/vli8KR</a>

**N.B.** Additional articles on implantable cardioverter-defibrillators at end of life are listed in this issue of Media Watch.

#### 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.

## Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <a href="http://goo.gl/8JyLmE">http://goo.gl/8JyLmE</a>

# Culturally competent palliative and hospice care training for ethnically diverse staff in long-term care facilities

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 29 March 2016 – Between 2013 and 2030, older adults 65 years and older of racial/ethnic populations in the U.S. is projected to increase by 123% in comparison to the Whites (Non-Hispanics). To meet this demand, training of ethnically diverse health staff in long-term care facilities in palliative and hospice care is imperative. The purpose of this study was to evaluate a palliative and hospice care training of staff in two nursing homes in Hawaii: a) to evaluate knowledge and confidence over three time periods; and, b) to compare staff and family caregiver satisfaction at end of program. The overall staff knowledge and confidence results were promising. The staff rated overall satisfaction of palliative care services lower than the family caregivers. Implications for future research, practice, and education with palliative and hospice care training of ethnically diverse nursing home staff is to include patient and family caregiver satisfaction of palliative and hospice care services, evaluation of effectiveness of cross-cultural communication theories in palliative and hospice care staff training, and support from administration for mentorship and development of these services in long term care facilities. http://goo.gl/Ef1IV7

**N.B.** In 2014, about 67,000 paid, regulated long-term care services providers served about nine million people in the U.S. Long-term care services were provided by 4,800 adult day services centers, 12,400 home health agencies 4,000 hospices, 15,600 nursing homes, and 30,200 assisted living and similar residential care communities. Source: Analytical & Epidemiological Studies (#37), National Center for Health Statistic, February 2016. <a href="http://goo.gl/AXUuOi">http://goo.gl/AXUuOi</a>

#### Related

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2016;22(3):141-149. 'Asian and native Hawaiian family caregiver satisfaction with palliative care services in nursing homes.' There is a need to address family caregiver and interdisciplinary nursing home staff communication based on culturally appropriate approaches for palliative as well as end of-life care services among Asians and native Hawaiians. <a href="http://goo.gl/2ez5ye">http://goo.gl/2ez5ye</a>

Noted in Media Watch, 23 November 2015, #437 (p.13):

■ JOURNAL OF PALLIATIVE MEDICINE | Online – 17 November 2015 – 'Patient-reported barriers to high-quality, end-of-life care: A multiethnic, multilingual, mixed-methods study.' This study in Burmese, English, Hindi, Mandarin, Tagalog, Spanish, and Vietnamese was held in multiethnic community centers in five California cities. Multiethnic patients report that high-quality end-of-life care is important to them; but unfortunately, a majority state that they have encountered barriers to receiving such care. <a href="http://goo.gl/bVG2fe">http://goo.gl/bVG2fe</a>

Noted in Media Watch: 9 February 2015, #396 (p.7):

■ U.S. (Oregon) | ABC News (Portland) – 1 February 2015 – 'Culturally sensitive palliative care represents new approach.' Palliative care has gained traction across the nation, but the culturally sensitive model embraced by Familias en Acción represents a new approach. <a href="http://goo.gl/LYIrBP">http://goo.gl/LYIrBP</a>

# Early introduction of palliative care and advanced care planning for children with complex chronic medical conditions: A pilot study

CHILD: CARE, HEALTH & DEVELOPMENT (British Association of Community Child Health) | Online – 29 March 2016 –Twenty families were enrolled and received an information packet; 15 met a palliative care (PC) team member. Of the 17 participating families who were reached and completed a post-study survey, 11 families had never heard of PC and 13 were unaware that the PC team existed. Most families perceived PC information as "very helpful" and "very important." All would recommend PC team services to others. Nine families followed up with the PC team, but none was prepared to complete an advanced care plan. Primary care providers reported lack of training in communicating bad news and conducting goals of care discussions. <a href="http://goo.gl/QZbA4G">http://goo.gl/QZbA4G</a>

Cont.

#### Related

LEARNING DISABILITY PRACTICE (Royal College of Nursing), 2016;19(3):16-22. 'How nurses grieve for children who die in their care.' The study ... suggests disenfranchised grief may be experienced by nurses who have cared for children with an intellectual disability who have died. Nurses may feel helpless because of their limited experience and knowledge... <a href="http://goo.gl/l6kYLB">http://goo.gl/l6kYLB</a>

#### **European Society for Clinical Nutrition & Metabolism**

## ESPEN guidelines on ethical aspects of artificial nutrition and hydration

CLINICAL NUTRITION (European Society for Clinical Nutrition & Metabolism) | Online - Accessed 31 March 2016 - The ESPEN Guidelines on ethical 'Aspects of Artificial Nutrition & Hydration' is focused on the adult patient and provides a critical summary for physicians and caregivers. Special consideration is given to end-of-life issues and palliative medicine; to dementia and to specific situations like nursing care or the intensive care unit. The respect for autonomy is an important focus of the guideline as well as the careful wording to be used in the communication with patients and families. Other principles of bioethics like beneficence, non-maleficence and justice are presented in the context of artificial nutrition and hydration. In this respect the withholding and withdrawing of artificial nutrition and/or hydration is discussed. Due to increasingly multicultural societies and the need for awareness of different values and beliefs an

elaborated chapter is dedicated to cultural and religious issues and nutrition. Last but not least topics like voluntary refusal of nutrition and fluids, and forced feeding of competent persons (persons on hunger strike) is included in the guideline. https://goo.gl/JbBOLI

### **Extract from ESPEN guidelines**

In end of life situations, the purpose of treatment and care is, above all, to improve the patient's quality of life. Decisions to withhold or withdraw a treatment that provides no benefit or has become disproportionate are from an ethical and a legal point of view identical. However it should be emphasized that if a therapy is being stopped, comfort care still has to be provided. This implies that even when artificial nutrition and hydration are discontinued, standard care has to be maintained.

Noted in Media Watch, 19 December 2011 #237 (p.12):

■ PSYCHO-ONCOLOGY | Online – 8 December 2011 – 'Hydration and nutrition at the end of life: A systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff.' Decrease in oral intake, weight loss, and muscular weakness in the last phases of a terminal illness, particularly in the context of the cachexia-anorexia syndrome, can be an important source of anxiety for the triad of patient, family, and health staff. The present literature review examines the emotional impact of reduced oral intake as well as perceptions and attitudes toward assisted nutrition and hydration for terminally ill patients at the end of life, among patients, family, and health care staff. <a href="http://goo.gl/X71Dr8">http://goo.gl/X71Dr8</a>

#### End-of-life care in Germany

# Legal basics in palliative care

DEUTSCHE MEDIZINISCHE WOCHENSCHRIFT, 2016;141(6):389-393. The German legal framework concerning end-of-life decisions is based on two pillars: the medical standards and the patient's autonomy. Every medical treatment, including life-saving and palliative measures, requires medical indication and, crucially, the patient's consent. Without the patient's consent even medically indicated treatment is prohibited. In other cases, complying with the patient's wishes, doctors have to treat symptoms the best they can. This includes palliative sedation accepting that the indicated medication may shorten life. It is prohibited to actively kill a patient to shorten his suffering. Assisting a suicide is only permitted if the suicide decision is made freely and on the patient's own responsibility. Businesslike suicide assistance is prohibited. <a href="https://goo.gl/w0Hd3r">https://goo.gl/w0Hd3r</a>

**N.B.** German language article

# Extending emotion and decision-making beyond the laboratory: The promise of palliative care contexts

EMOTION (American Psychological Association) | Online – 28 March 2016 – Although laboratory-based research on emotion and decision-making holds the distinct advantage of rigorous experimental control conditions that allow causal inferences, the question of how findings in a laboratory generalize to real-world settings remains. Identifying ecologically valid, real-world opportunities to extend laboratory findings is a valuable means of advancing this field. Palliative care (PC) – or care intended to provide relief from serious illness and aging-related complications during treatment or at the end of life – provides a particularly rich opportunity for such work. Here, the authors present an overview of PC, summarize existing research on emotion and PC decision-making, highlight challenges associated with conducting such research, outline examples of collaborative projects leveraging PC as a context for generating fundamental knowledge about emotion and decision-making, and describe the resources and collaborations necessary to conduct this type of research. In sum, PC holds unique promise as an emotionally laden context in which to answer fundamental questions about emotion and decision-making that extends our theoretical understanding of the role of emotion in high-stakes decision-making while simultaneously generating knowledge that can improve PC implementation. http://goo.gl/nRWyNO

#### Related

- COPD: JOURNAL OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE | Online 30 March 2016 'End-of-life discussion, patient understanding and determinants of preferences in very severe COPD Patients: A multi-centric study.' Less than 50% of the patients retained a full comprehension of the options [proposed] at 24 hours. About half of the patients who died in the follow-up period were not treated according to their wishes. <a href="http://goo.gl/TrgvEA">http://goo.gl/TrgvEA</a>
- HOME HEALTHCARE NOW, 2016;34(4):228-229. 'It's time to talk: Starting a conversation about discontinuing medications at end of life.' Although considerable attention is being paid to medication reconciliation ensuring that patients are continued on prescribed medications as they transition across different settings of care little attention has been paid to developing systematic approaches to stopping medications at transitions of care, particularly for patients near the end of life. In hospice, helping patients reduce the number of medications may help to improve patient's quality of life and reduce medication-related side effects. <a href="http://goo.gl/Yln21x">http://goo.gl/Yln21x</a>

# From non-issue to healthcare crisis: A historical review of aging and dying with an intellectual and developmental disability

INTELLECTUAL & DEVELOPMENTAL DISABILITIES (American Association on Intellectual & Developmental Disabilities), 2016;54(2):151-156. Individuals with intellectual and developmental disabilities are living unprecedentedly longer lives primarily due to the long-term benefits of the deinstitutionalization movement and widespread improvements in health outcomes. However, the consequences of this protracted aging process are significant, complex, and often poor not only for the individuals and their caregivers, but for the mainstream healthcare community. This article will explore, utilizing a constructionist perspective, how these challenges evolved from a non-issue to an impending crisis in less than 25 years. Additionally, present-day efforts by researchers, policymakers, and practitioners to address these challenges will be explored and recommendations will be made for future directions. <a href="http://goo.gl/9cKv4P">http://goo.gl/9cKv4P</a>

Noted in Media Watch, 28 March 2016, #455 (p.9):

BMC PALLIATIVE CARE | Online – 24 March 2016 – 'Developing research priorities for palliative care of people with intellectual disabilities in Europe: A consultation process using nominal group technique.' The proposal of four major priority areas and a range of minor themes for future research in intellectual disability, death, dying and palliative care will help researchers to focus limited resources and research expertise on areas where it is most needed and support the building of collaborations. http://goo.gl/fNxm6x

Noted in Media Watch, 8 February 2016, #448 (p.12):

- EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(1):45-47. 'Palliative care for people with intellectual disabilities: The European Association for Palliative Care White Paper in a nutshell.' The Taskforce on Palliative Care for People with Intellectual Disabilities of the European Association for Palliative Care (EAPC) recently published a White Paper containing 13 norms and related statements, real-life examples, and available resources. The EAPC White Paper represents a Europe-wide consensus on what should be aimed for in order to achieve good PC for people with intellectual disabilities. Journal contents page: <a href="http://goo.gl/ql/wex7">http://goo.gl/ql/wex7</a>
  - 'Defining Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe, Using Delphi Methods: A White Paper from the European Association of Palliative Care,' *Palliative Medicine*, 11 August 2015. [Noted in Media Watch, 17 August 2015, #423 (p.19)] <a href="http://goo.gl/FQUsti">http://goo.gl/FQUsti</a>

**N.B.** Additional articles on palliative care for people living with intellectual disabilities are listed in this issue of Media Watch.

#### Historical perspective

## Evolution of caring for dying patients in intensive care units in the U.S. from 1960-1980.

INTERNATIONAL JOURNAL FOR HUMAN CARING (International Association for Human Caring), 2016: 20(1):2-7. This study examines the evolution of caring for dying patients in intensive care units in the United States from 1960-1980. Historical research method was used. Data were obtained from electronic databases, journals, textbooks, and interviews of 3 intensive care nurses. The three major themes were: 1) Lack of formal preparation for care of the dying; 2) Increased workload and stress; and, 3) Becoming more concerned about quality of end-of-life care. Nurses and healthcare professionals could use this knowledge as a source to compare and develop their future practices in care for dying patients in the intensive care units. <a href="https://goo.gl/w7HRfJ">https://goo.gl/w7HRfJ</a>

# Supporting generalist nurses in the rural setting with the introduction of a clinical assessment process

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2016;22(3):120-128. The aim of this research was to evaluate the implementation of an assessment process for general nurses involved in providing end-of-life care. A mixed-method, three-phased study was conducted on a medical ward at a regional hospital in a rural setting. Participating nurses completed a questionnaire about their awareness levels of the five validated scales included in the assessment of patients receiving palliative care (PC). Auditing of the completed assessment forms was conducted at the interim and post data collection points and focus groups were conducted in the final phase. Analysis of the data revealed that nurses were able to integrate the use of this assessment process into the care of this group of patients. The author concludes, while nurses working in rural settings require general clinical knowledge of a wide range of patient groups, validated assessment scales can assist them in the provision of evidence-based PC. http://goo.gl/mV2IRN

#### Related

• AGE & AGING | Online – 28 March 2016 – 'Geographic variation of inpatient care costs at the end of life.' The results of this study provide evidence of additional costs associated with remote locations. If length of stay and costs are to be reduced, alternative care provision is required in rural areas. Lower costs in other urban areas compared with large urban areas may be due to urban centres incurring higher costs through case-mix and clinical practice. If inequalities are driven by hospital admission, for an end-of-life scenario, care delivered closer to home or home-based care seems intuitively attractive and potentially cost-saving. <a href="http://goo.gl/6Xbo84">http://goo.gl/6Xbo84</a>

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

# Hearing loss in hospice and palliative care: A national survey of providers

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 April 2016 – Age-related hearing loss can impair patient-provider communication about symptom management, goals of care, and end-of-life decision making. Of 510 responses (57% practiced hospital-based palliative care, 45% hospice), 315 were physicians, 50 nurses, 48 nurse practitioners (NPs), 58 social workers, and 39 chaplains. Ninety-one percent reported that hearing loss has some or great impact on the quality of care for older adults. Eighty-eight percent recalled a situation where hearing loss created a communication problem with a patient, and 56% a communication problem with a caregiver. Eighty-seven percent of physicians, nurses, and NPs reported not screening for hearing loss. While 61% felt comfortable with their communication skills for patients with hearing loss, only 21% reported having received formal training in its management, 31% were unfamiliar with resources for patients with hearing loss, and 38% had never heard of a pocket talker amplification device. Hospice and palliative medicine providers believe age-related hearing loss impacts care yet most do not screen. While they feel they are managing well, few have formal training. Knowledge about management approaches and resources is suboptimal. <a href="https://goo.gl/DCC813">https://goo.gl/DCC813</a>

#### Selected articles on hearing loss in palliative care

- HEALTH & SOCIAL CARE IN THE COMMUNITY | Online 5 January 2016 'One of society's most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deaf-blind people.' No empirical studies specifically examining the experience of vulnerability of deaf-blind people were found. However, deaf-blind people describe feelings of vulnerability in studies exploring their experiences more generally, and in personal accounts of living with the impairment. [Noted in Media Watch, 11 January 20167, #444 (p.10)] <a href="https://goo.gl/KprD7r">https://goo.gl/KprD7r</a>
- JOURNAL OF PALLIATIVE MEDICINE | Online 13 April 2015 'Hearing loss in palliative care.' Despite its high prevalence, there is remarkably little written on the impact of hearing loss in the palliative care literature. The authors describe simple methods of screening patients for hearing loss, and suggest that practical approaches should be used universally in patient encounters. These include facing the patient, pitching one's voice low, using a pocket talker, and creating a hearing-friendly environment when planning a family or group meeting. [Noted in Media Watch, 20 April 2015, #406 (p.11)] <a href="http://goo.gl/RKJGbh">http://goo.gl/RKJGbh</a>
- HEC FORUM, 2002;14(3):197-208. 'American Sign Language and end-of-life care: Research in the deaf community.' The authors describe a community-based participatory research process used to develop a means of discussing end-of-life care needs of deaf seniors. [Noted in Media Watch, 20 August 2012, #267 (p.12, under 'Worth Repeating')] <a href="https://goo.gl/y1F4fe">https://goo.gl/y1F4fe</a>

### Barriers in palliative care in China

THE LANCET, 2016;387(10025):1272. China ranked 71<sup>st</sup> of 80 countries [in the 2015 Quality of Death Index<sup>1</sup>] and was reported to be "facing difficulties from slow adoption of palliative care (PC) and a rapidly aging population." In view of the size of the Chinese population, this finding is very worrying, and we recognise that some barriers do exist in the development of PC in China. First, most Chinese people believe that only dying patients need PC. Affected by the traditional view that people with terminal illnesses have short life expectancies, patients and their families become desperate and find it difficult to accept PC emotionally. Second, financial cost and the absence of national strategies and guidelines are major problems. Third, the shortage of professional PC staff is severe. http://goo.gl/Q1i0cD

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <a href="http://goo.gl/JsSbW3">http://goo.gl/JsSbW3</a>

Noted in Media Watch, 15 February 2016, #449 (p.11):

\* CLINICAL JOURNAL OF ONCOLOGY NURSING (Oncology Nursing Society), 2016;20(1):e16-e19. 'Hospice and palliative care: Development and challenges in China.' This article describes the status of palliative care (PC) services in China, their historic development, and the barriers to their advancement. A significant amount of work is needed to meet the standards of international PC societies. Nurses and other health providers who are engaged in PC should be well trained regarding the principles and procedures of PC to ensure quality end-of-life care. <a href="https://goo.gl/2K1w10">https://goo.gl/2K1w10</a>

N.B. Additional articles on end-of-life care in China are listed in this issue of Media Watch.

#### End-of-life care in Japan

## Terminally ill cancer patients who choose to die at home may live longer

MEDICAL DAILY | Online - 28 March 2016 - While many might prefer the familiar comforts of their home as their final resting place, the majority spend their last days inside a hospital, in part because they fear the palliative care they would receive elsewhere may be worse. A new study, however, may go a long way towards alleviating that particular worry. Poring over the medical records of just over 2,000 terminally ill cancer patients, the researchers found those who received hospice care at home actually slightly outlived their hospital-based counterparts. "The cancer patient and family tend to be concerned that the quality of medical treatment provided at home will be inferior to that given in a hospital and that survival might be shortened; however, our finding - that home death does not actually have a negative influence on the survival of cancer patients at all, and rather may have a positive influence - could suggest that the patient and family can choose the place of death in terms of their preference and values," said lead author Dr. Jun Hamano, of the University of Tsukuba in Japan... Hamano and his colleagues studied 2,069 terminally ill patients from various medical centers scattered throughout Japan. Of these, 1,582 patients obtained their hospice care at a hospital and 487 opted to receive it at home. The home patients lived noticeably longer than the former group, even after taking into account other factors like age or disease severity. The study is only the latest to show the potential benefits of home-based hospice care. http://goo.al/4SEiB2

1. 'A multicenter cohort study on the survival time of cancer patients dying at home or in hospital: Does place matter?' Cancer, 28 March 2016. <a href="http://goo.gl/AO9Vse">http://goo.gl/AO9Vse</a>

#### Selected articles on the economics of home-based palliative care

- CANADA | iPolitics 29 February 2016 'Palliative care at home reduces overall costs in last month of patient's life: Study.' A new Canadian study suggests that boosting palliative home-based care services in the last month of a patient's life reduces healthcare costs overall by keeping patients out of hospitals. The research suggests that savings come from more attention to patients from palliative care nurses, which leads to avoiding or shortening hospitalizations. [Noted in Media Watch, 7 March 2016, #452 (p.2)] <a href="http://goo.gl/JNL8JI">http://goo.gl/JNL8JI</a>
  - 'Temporal association between home nursing and hospital costs at end of life in three provinces,' Current Oncology, 2016;23:S42-S51: http://goo.gl/MuBD9M
- U.S. | The Wall Street Journal 27 September 2015 'How house calls can cut medical costs.'
  Evidence has mounted that primary care at home, though not inexpensive to provide, can be more economical than a constant cycle of emergency-room visits and hospital stays. According to a study published last year...<sup>1,2</sup> [Noted in Media Watch, 5 October 2015, #430 (p.5)] <a href="https://goo.gl/382Htf">https://goo.gl/382Htf</a>
  - 1. 'Effects of home-based primary care on Medicare costs...,' *Journal of the American Geriatrics Society*, 2014;62(10):1825-1831. http://goo.gl/VFcd3W
  - 2. 'Better access, quality, and cost for clinically complex veterans with home-based primary care,' *Journal of the American Geriatrics Society*, 2014;62(10):1954-1961. http://goo.gl/abdJzJ

U.S. | The Cochrane Library (Cochrane Pain, Palliative & Supportive Care Group) – 6 June 2013 – 'Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers.' On the basis of 23 studies the authors found when someone with an advanced illness gets home palliative care, their chances of dying at home more than double. Home PC services help reduce the symptom burden people may experience as a result of advanced illness, without increasing grief for family caregivers after the patient dies. [Noted in Media Watch, 10 June 2013, #309 (p.13)] <a href="http://goo.gl/N6VVqC">http://goo.gl/N6VVqC</a>

### Reasons behind providing futile medical treatments in Iran: A qualitative study

NURSING ETHICS | Online – 21 March 2016 – Despite their negative consequences, evidence shows that futile medical treatments are still being provided, particularly to terminally ill patients. The main theme of the study was "having an obligation to provide medical treatments despite knowing their futility." This theme consisted of three main categories including patients' and family members' request for continuing life-sustaining treatments, healthcare professionals' personal motives, and organizational atmosphere and structure. Different personal and organizational factors contribute to providing futile medical treatments. Promoting the structure and the function of hospital ethics committees, establishing and developing home care facilities, increasing the number of palliative care centers and hospices, and educating healthcare professionals, patients, and family members about the services and the benefits of such centers can facilitate making wise decisions about continuing or discontinuing treatments which have been labeled as futile. http://goo.gl/vsz2GH

#### Related

MATERIA SOCIO MEDICA, 2016;28(2):151-155. 'Nurses' perceptions of futile medical care.' According to the literature, futile care cannot be easily defined in medical sciences, and ethical dilemmas surrounding this phenomenon are very complex. Considering the key role of nurses in patient care and end-of-life decision-making and their great influence on the attitudes of patients and their families, support and counseling services on medical futility and the surrounding ethical issues are necessary for these members of healthcare teams. http://goo.gl/ETRd7M

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

#### Nurse-led end of life care in London is helping people have more control over their last days

NURSING STANDARD (Royal College of Nursing) | Online – 23 March 2016 – An end-of-life care service is providing joined-up care for patients. Care coordinators arrange packages of care so patients can die in the place of their choice – often at home. The result is high satisfaction rates among patients, families and staff. Over the course of the pilot so far, 49% of patients known to the service died at home, while 36% died in hospital. Where patient preference was known, three quarters of people known to the service died in their preferred place of death. <a href="http://goo.gl/RqWgkl">http://goo.gl/RqWgkl</a>

Noted in Media Watch, 26 October 2015, #433 (p.6):

- U.K. (England) | Pan-London End of Life Alliance 19 October 2015 'Is London the worst place to die?' The quality of end-of-life care (EOLC) received in London currently under performs against national averages. The London Assembly Health Committee will examine EOLC in the capital and the barriers certain groups face. <a href="http://goo.gl/rMvweZ">http://goo.gl/rMvweZ</a>
  - 'A review of specialist palliative care provision and access across London,' London Cancer Alliance, PallE8 & Marie Curie, 18 September 2015. [Noted in Media Watch, 21 September 2015, #428 (p.5)] <a href="https://goo.gl/Gacy6q">https://goo.gl/Gacy6q</a>

## Validation of a model of family caregiver communication types and related caregiver outcomes

PALLIATIVE & SUPPORTIVE CARE | Online – 1 April 2016 – Caring for the family is included as one of the eight domains of quality palliative care, calling attention to the importance of the family system and family communications about cancer during care and treatment of the disease. Previously, a model of family caregiver communication defined four caregiver communication types – manager, carrier, partner, lone – each with a unique communication pattern. The purpose of the present study was to extend the model of family caregiver communication in cancer care to further understand the impact of family communication burden on caregiving outcomes. This study illustrates the impact of family communication on caregiving and increases our knowledge and understanding about the role of communication in caregiver burden. The research provides the first evidence-based validation for a family caregiver communication typology and its relationship to caregiver outcomes. Future research is needed to develop and test interventions that target specific caregiver types. http://goo.gl/sDEtxD

#### Ethical case study of the researcher-participant relationship in end-of-life research

WESTERN JOURNAL OF NURSING RESEARCH | Online – 22 March 2016 – Nurse-researchers (N-R) studying interventions for patients at the end-of-life may become close with participants due to the nature of interactions within the research protocol. In such studies, participants may request further interactions that would constitute clinical care beyond the scope of the protocol. N-R may feel a conflict of values between their obligation to the research goals and their inclinations and obligations as nurses to care for their patients. N-R in this situation aspire to honor the bonds developed through close contact and ensure participants receive standard of care while maintaining standards of research ethics. Analysis of a case and review of applicable concepts in research ethics, including ethical relationships, therapeutic misconception, equipoise, and population vulnerability, are used to develop recommendations regarding the decision parameters for similar cases. <a href="http://goo.gl/ZXOOJj">http://goo.gl/ZXOOJj</a>

### **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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- 1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
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- 5. 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.
- **6.** 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.

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- JOURNAL OF PALLIATIVE MEDICINE, 2016;19(5):1-2. 'Physician-assisted death does not improve end-of-life care.' In their recent article 'Geographic variation of hospice use patterns at the end of life'¹ Wang et al propose that the Oregon Death with Dignity Act (DWDA) has stimulated "more open conversations and careful evaluation of options" in end-of-life care (EOLC) and "increased hospice referrals and reduced potentially concerning patterns of hospice use in the state." The authors appear to see causation where only correlation exists. Further, they misrepresent the sources cited to support this claim: One... specifically rejects the notion that the DWDA is directly responsible for improving terminal care in Oregon; another ... posits a different relationship between DWDA and hospice care; and the third ... simply cites Tolle and posits a loose "association" between the presence of DWDA and Oregon's excellence in EOLC. All three, it should be noted, were published between 8 and 14 years ago. http://goo.gl/VVVf66
  - 1. 'Geographic variation of hospice use patterns at the end of life,' *Journal of Palliative Medicine*, 14 July 2015. [Noted in Media Watch, 20 July 2015, #419 (p.14)] http://goo.gl/gjVwMy

## **Media Watch: Online**

#### International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/zJ7jOo

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: <u>HTTP://GOO.GL/JNHVMB</u>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): http://goo.gl/XrhYCH

#### Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): http://goo.gl/AhlgvD

## **Europe**

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

HUNGARY | Hungarian Hospice Foundation: http://goo.gl/5d1l9K

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

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