## 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.

## 11 December 2017 Edition | Issue #542



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Compiled & Annotated by Barry R. Ashpole

As death approaches: Scroll down to <u>Specialist Publications</u> and 'Caregiver anticipatory grief: Phenomenology, assessment and clinical interventions' (p.10), in *Current Opinion in Supportive & Palliative Care*.

### **Canada**

### Better planning could save Ontario hundreds of millions in health costs: Auditor General

ONTARIO | The Globe & Mail (Toronto) - 6 December 2017 - Hundreds of millions of dollars could be saved every year in drug purchases and health treatments if Ontario's government planned more thoughtfully and responded more quickly to problems, according to the province's Auditor General. Auditor General Bonnie Lysyk said her office found numerous instances where money could have been saved over the past year by the provincial government, according to her far-ranging annual report to Queen's Park. The 1,119-page report highlighted possible savings in health care, the electrical system and services for newcomers, proof that the government needs to "plan better." she said. "A theme that was central to almost all of our audits this year was the need for government to plan better and sometimes to just have a plan in the first place," Ms. Lysyk said in a statement. Looking for savings in Ontario's \$52-billion annual health budget, Ms. Lysyk's office found that the province is spending hundreds of millions of dollars too much on generic drugs, laboratory services and stem cell treatments. https://goo.gl/Guk2Aa

# Extract from Ontario Auditor General's report: Palliative care treatment plans

Only 28% of palliative treatment plans (PTPs) were reviewed. The percentage of PTPs reviewed within the recommended time frame also varied significantly among hospitals, ranging from 1% to 96%. Cancer Care Ontario (CCO) informed us that the review of PTPs is a new initiative and therefore has not been a priority relative to the review of curative treatment plans. CCO also informed us that this new initiative has been slowly ramping up since 2013... The minimum review target for PTPs at each centre in 2017/18 will be 10%, with an overall provincial target of 30%.

## Specialist Publications

'Withholding and withdrawing life support: Difficult decisions around care at the end of life' (p.9), in Canadian Journal of Anesthesia.

1. 'Annual Report 2017,' The Office of the Auditor General of Ontario, Volumes 1 & 2, December 2017. **Download, view at:** <a href="https://goo.gl/XUmEGi">https://goo.gl/XUmEGi</a>

### Ambiguity about end-of-life wishes can lead to conflict among decision-makers

THE LAWYERS WEEKLY | Online – 4 December 2017 – When expressing end-of-life wishes in a health care directive, clients often want to include a general clause leaving it up to their appointed decision-maker to determine whether care should be withdrawn. Generality does serve a purpose, as it is impossible to foresee every possible scenario. However, it can also lead to conflicts about whether that discretion is being appropriately exercised. Three cases provide examples of conflicts stemming from confusion about the incapable person's wishes and concerns about the decisions being made on their behalf. <a href="https://goo.gl/WbFgkE">https://goo.gl/WbFgkE</a>

Noted in Media Watch 27 June 2016 (#468, p.11):

NURSING IN CRITICAL CARE, 2016;21(4):193-194. 'Treatment withdrawal, allow a natural death, passive euthanasia: A care-full choice of words.' When we talk about concepts and care at the end of life, it is important to be clear to ourselves and to others about what we mean, what we say and what our motivations are behind the care given. When we talk to patients/families and to our colleagues, there can be no place for ambiguity or euphemisms. Abstract: <a href="http://goo.gl/NsQAtS">http://goo.gl/NsQAtS</a>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | Policy Options 7 December 2017 'Faith-based care and medical assistance in dying.' A recent poll specifically asked whether a faith-based institution should have the option to refuse to provide medical assistance in dying (MAiD).¹ The poll asked responders to consider the following options in relation to long-term care centres/homes: "Setting aside your own views on assisted dying for a moment, do you think a religiously affiliated nursing home should be able to say no on moral grounds and patients who want a doctor-assisted death would be moved to another facility or be required by law to allow these procedures at their facilities?" The question should have been even more specific: the pollsters did not differentiate between privately and publicly funded nursing homes, and not all nursing homes, religiously affiliated or not, are publicly funded. Furthermore, it is not widely known that currently there are no federal or provincial laws mandating such procedures in faith-based facilities. Taking into account these limitations, the poll results remain valuable. More than half the respondents said religiously affiliated nursing homes should be allowed to not provide MAiD and to move patients wishing MAiD to another facility, while 45% believed that religiously affiliated nursing homes should be required by law to allow MAiD to be performed in their facilities. https://goo.gl/hQaTpy
  - 1. 'Faith and religion in public life: Canadians deeply divided over the role of faith in the public square,' Angus Reid Institute, November 2017. **Download/view at:** https://goo.gl/xbx4Qa

### 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: <a href="http://goo.gl/5CHoAG">http://goo.gl/5CHoAG</a>



Media Watch: Behind the Scenes http://goo.gl/XDjHxz

## U.S.A.

### Most people want to die at home, but many land in hospitals getting unwanted care

THE WASHINGTON POST | Online - 9 December 2017 - Where do you want to die? When asked, the vast majority of Americans answer with two words: "At home." Despite living in a country that delivers some of the best health care in the world, we often settle for end-of-life care (EoLC) that is inconsistent with our wishes and administered in settings that are unfamiliar, even dangerous. In California, for example, 70% of individuals surveyed said they wish to die at home, yet 68% do not. Instead, many of us die in hospitals, subject to overmedication and infection, often after receiving treatment that we do not want. Doctors know this, which may explain why 72% of them die at home. Using data from the Dartmouth Atlas - a source of information and analytics that organizes Medicare data by a variety of indicators linked to medical resource use - the authors recently ranked geographic areas based on markers of EoLC quality, including deaths in the hospital and number of physicians seen in the last year of life.3 People are accustomed to ranking areas of the country based on availability of high-quality arts, universities, restaurants, parks and recreation and healthcare quality overall. But we can also rank areas based on how they treat us at an important moment of life: when it's coming to an end. It turns out not all areas are created equal. Critical questions abound. For example, why do 71% of those who die in Ogden, Utah, receive hospice care, while only 31% do in Manhattan? Why is the rate of deaths in intensive care units in Cedar Rapids, Iowa, almost four times that of Los Angeles? Why do only 12% of individuals in Sun City, Arizona, die in a hospital, while 30% do in McAllen, Texas? Race and other demographics in a given area certainly matter. One systematic review of more than 20 studies showed that African American and Hispanic individuals utilize advance care planning and hospice far less than whites. More research is needed to explore these differences and to close these gaps and demand high-quality, personalized care for people of all races. But race and demographics don't provide all the answers. https://goo.gl/il.C997

### **Specialist Publications**

'Palliative care providers' practices surrounding psychological distress and treatment: A national survey' (p.13), in American Journal of Hospice & Palliative Medicine.

'Characterizing the role of U.S. surgeons in the provision of palliative care: A systematic review and mixed-methods meta-synthesis' (p.13), in *Journal of Pain & Symptom Management.* 

'Emergency medical services provider experiences of hospice care' (p.14), in *Prehospital Emergency Care*.

- 'Final chapter: Californians' attitudes and experiences with death and dying,' California Health Care Foundation, February 2012. [Noted in the 20 February 2012 issue of Media Watch (#241, p.3)] Download/view at: <a href="https://goo.gl/pUoxNW">https://goo.gl/pUoxNW</a>
- 'End-of-life care intensity for physicians, lawyers, and the general population,' *Journal of the American Medical Association*, 2016;315(3):303-305. [Noted in the 25 January 2016 issue of Media Watch (#446, p.4)] Abstract: <a href="http://goo.gl/TdqUx8">http://goo.gl/TdqUx8</a>
- 3. 'Policy and politics to drive change in end-of-life care: Assessing the best and worst places to die in America,' *Generations*, 2017;41(1):94-101. **Abstract:** https://goo.gl/n59YmU
  - **N.B.** The focus of the Spring 2017 issue of *Generations* is "reforming advanced illness and end-of-life care." Journal contents page: <a href="https://goo.gl/amNnbl">https://goo.gl/amNnbl</a>
- 4. 'End-of-life care for people with cancer from ethnic minority groups: A systematic review,' *American Journal of Hospice & Palliative Medicine*, published online 29 December 2014. [Noted in the 5 January 2015 issue of Media Watch (#391, p.6)] **Abstract:** <a href="https://goo.gl/m5aYgm">https://goo.gl/m5aYgm</a>

### Readmissions project brings 17% drop in hospitalizations

MCKNIGHT'S LONG-TERM CARE NEWS | Online - 6 December 2017 - A Centers for Medicare & Medicaid Services (CMS) program created to reduce hospital readmissions among nursing home residents has shown positive results after three years. CMS said the program helped reduce potentially avoidable hospitalizations by 17% among participating facilities, known as Enhanced Care & Coordination Providers (ECCPS). The initiative also saved Medicare nearly \$50 million, CMS said in a report on its Initiative to Reduce Avoidable Hospitalizations among Nursing Facility Residents. The program, which ran from 2013 to 2016, required ECCPs to employ registered nurses or ad-

vanced practice registered nurses to provide support, clinical care, and education to other staff. https://goo.gl/wGpGss

# Extract from McKnight's Long-Term Care News article

The Centers for Medicare & Medicaid Services touted the initiative's "major successes," including changing facility culture toward treating residents onsite, empowering staff and improving their communication skills, and increasing facilities' focus on end-of-life care and planning.

## **International**

### 8 in 10 patients want detailed prognosis

SOUTH KOREA | Korea Bizwire (Seoul) - 8 December 2017 - A new survey has found nearly 8 in 10 South Korean patients want to receive a detailed prognosis consisting of life expectancy and whether or not their illness is curable when they are diagnosed with a serious illness. Findings from the survey ... indicated that the social perception of death and life prolongation have changed drastically on the back of growing support for advanced healthcare directives, and the so-called dying-well law that allows patients to die with dignity. Recently a hearing was held at Seoul National University Hospital to examine the findings from hospice law research projects, following the hospice care amendment that was passed earlier this year allowing terminally ill patients such as cancer patients to decide whether or not to continue treatment. Nearly 80% of the respondents said they wanted full disclosure of their medical status when receiving a prognosis, with over 40% wanting to be let in on their health status even if their illness wasn't curable. Around 1 in 4 people were most interested in life expectancy, while 15.2% were more concerned with the availability of care services. https://goo.gl/qkkBWz

### **Specialist Publications**

'Changes in older people's care profiles during the last 2 years of life, 1996-1998 and 2011-2013: A retrospective nationwide study in Finland' (p.9), in *BMJ Open*.

'Patient journeys through the palliative care system in Germany' (p.11), in European Journal of Palliative Care.

'Deaths in France: Characteristics, place of death, hospitalisations and use of palliative care during the year before death' (p.15), in Revue d'Épidémiologie et de Santé Publique.

'A novel family dignity intervention for enhancing and informing holistic palliative care in Asia: study protocol for a randomized controlled trial' (p.15), in *Trials*.

Noted in Media Watch 27 November 2017 (#540, p.5):

SOUTH KOREA | The Korea Herald (Seoul) – 22 November 2017 – 'Korea sees first legitimate case
of patient refusing life support.' The patient, in his 50s, who suffered from gastrointestinal cancer,
refused to receive life-prolonging treatments by signing a Physician Order for Life-Sustaining Treatment about a month ago. <a href="https://goo.gl/8ittml">https://goo.gl/8ittml</a>.

### Dying to work: Parish council first to sign up to charter

U.K. (England) | The Northern Echo (Darlington, County Durham) – 7 December 2017 – A parish council has become the first to sign up to a charter pledging to support employees with terminal illnesses. After agreeing to sign up to the Trade Union Congress' Dying to Work charter in October, Brandon and Byshottles Parish Council officially made the pledge this week. The campaign is aimed at getting organisations to pledge to support their employees should they be diagnosed with a terminal illness. The campaign is calling for terminal illness to be made a pro-

tected characteristic of employment. The parish council has three employees – a clerk, officer and cleaner. https://goo.gl/4GFSm9

### **Specialist Publications**

'An employer health incentive plan for advance care planning and goal-aligned care' (p.14), in Population Health Management.

Noted in Media Watch 22 August 2016 (#476, p.6):

U.K. (England | LocalGov – 18 August 2016 – 'First county to back Dying to Work campaign.' Nottinghamshire has become the first county council to sign up to a new charter helping employees with terminal illnesses stay in their job. The Trade Union Council's Dying to Work Voluntary Charter gives employees a "protected period" in which they can not be dismissed from their role as a result of their terminal illness. <a href="http://goo.gl/Y2Nlvu">http://goo.gl/Y2Nlvu</a>

#### End-of-life care in India

### Policy on premature release of terminally ill prisoners

INDIA (Punjab) | The Times of India (Chandigarh) – 6 December 2017 – The Punjab government has introduced a policy for the premature release of terminally ill and mentally incapacitated convicts who have been sentenced to life imprisonment. Earlier, these convicts used to languish inside jails despite chronic illness, but now they would be eligible for premature release as soon as they have completed 10 years of their sentence. Physical and mental examination would be conducted by a medical board. The policy has come as a blessing in the cases of terminally ill prisoners suffering from cancer, AIDS, failure of both kidneys or those in the last

stage of life. When medical board certifies that the prisoner is actually suffering from a terminal illness, his case will be immediately considered for premature release under Article 161 of the Constitution of India. https://goo.gl/uATW1N

### **Specialist Publications**

'Systematic review of aged care interventions for older prisoners' (p.8), in Australasian Journal of Ageing.

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

#### Payout after woman was kept alive against her will

U.K. (England) | BBC News – 6 December 2017 – The family of an 81-year-old woman has received a £45,000 payout after she was kept alive against her will. Brenda Grant made a living will stating she feared degradation and indignity more than death after seeing her mum lose independence through dementia. But the George Eliot hospital, in Nuneaton, Warwickshire, misplaced the document and she was artificially fed for 22 months. Mrs. Grant, from Nuneaton, had an advance directive (AD) drawn up to say if she were no longer of sound mind or had suffered from a list of medical ailments, she should not have

treatment to prolong her life. It also confirmed she should not be given food, but that distressing symptoms should be controlled by pain relief even though the treatment might shorten her life. The George Eliot Hospital Trust admitted liability and in an out-of-court settlement agreed to pay £45,000. In a letter, it stated: "It is accepted that the trust failed to act in accordance with the deceased's AD and failed to store the AD in a way that it could easily be noted." The trust said it had now begun recording the existence of an AD on the front page of a patient's notes. <a href="https://goo.gl/gT2kfL">https://goo.gl/gT2kfL</a>

### U.K. hospices warned against joint venture with undertaker tycoon

U.K. (England) | *The Guardian* (London) – 5 December 2017 – Hospices for the dying have been warned against a controversial scheme encouraging them to branch into the funeral business with an undertaker turned tycoon who wrote the book *How to Become Dead Rich*. Hospice Funerals is a joint venture between St. Margaret's hospice in Taunton and Memoria. Under the plan, hospices that sign up, for a £10,000 fee, will be able to offer low-cost funerals to the families of patients who were in their care. It has been praised by some as an innovative way for hospices to raise funds; but others are concerned that bereaved families will feel pressured to choose the funeral scheme as a way of paying back the hospices for their care. The initiative, to be advertised on TV next year, threatens to sour relations between hospices and local funeral directors and raises ethical questions about how funds are raised to care for the dying. Some hospices are concerned that the scheme could harm the sector. Peter Hartland, the chief executive of St. Luke's hospice in Sheffield, said: "I worry that families using our free services might feel under moral pressure to use a funeral service branded under the hospice banner, believing that because their loved one had received care from our charity, they should repay us. Worse, some might feel that we offered those funeral services to profit from such families." <a href="https://goo.gl/L9BQG7">https://goo.gl/L9BQG7</a>

### End-of-life care in England

### End of Life Care Profiles: December 2017 update

U.K. (England) | Public Health England – 5 December 2017 – The end-of-life (EoL) care profiles have been developed by Public Health England's National End-of-Life Care Intelligence Network to support the Na-



tional Health Service, local authorities, health services and other interested stakeholders to monitor comparative information on factors that describe population trends associated with the EoL. Providing care at the EoL often involves the interaction of many different care agencies. The profiles are intended to help commissioners and providers to get a clearer picture of the EoL care needs of their local populations. They are grouped into the following domains: Place of Death, Underlying Cause of Death, Mortality Rates, Death in Usual Place of Residence, Care home use at EoL, Dementia (includes Alzheimer's disease) and other relevant indicators. In each domain and where possible, information is presented by Government Office Region, Strategic Clinical Network, Clinical Commissioning Group, County & Unitary Authority, and District & Unitary Authority. **Download/view report at:** https://goo.gl/owZZyt

### "Opiophobia" has left Africa in agony

AFRICA (Uganda) | *The New York Times* – 4 December 2017 – The American delegation to the International Narcotics Control Board, a United Nations agency, "uses frightening war-on-drugs rhetoric," said Meg O'Brien, the founder of Treat the Pain, an advocacy group devoted to bringing palliative care to poor countries. "That has a chilling effect on developing countries," she said. Uganda has implemented an innovative solution. Here, liquid morphine is produced by a private charity overseen by the government. And with doctors in short supply, the law lets even nurses prescribe morphine after specialized training. About 11% of Ugandans needing morphine get it. Inadequate as that is, it makes Uganda a standout not just in Africa, but in the world. Yet there is very little opioid abuse here; alcohol, marijuana and khat are

far bigger problems. A recent major study ... described a "broad and deep abyss" in access to painkillers between rich countries and poor ones. The U.S., the report said, produces or imports 31 times as much narcotic pain-relievers it needs whether in legal or illegal form: morphine, hydrocodone, heroin, methadone, fentanyl and so on. Haiti, by contrast, gets slightly less than 1% of what it needs. And Nigeria, on a per-capita basis, gets only a quarter of what Haiti gets: 0.2% of its need. Even in big countries with domestic pharmaceutical industries, citizens still get short changed on pain relief, the report said. India and Indonesia, the second- and fourth-most populous countries on the planet, each supply only 4% of their own needs. Russia is at 8%. China, at 16%, barely beats Uganda. https://goo.gl/5esJMo

'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' The Lancet, published online 12 October 2017. [Noted in the 16 October 2017 issue of Media Watch (#534, p.14)] Full text: https://goo.gl/i7r9M1

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

AUSTRALIA | Lexology – 7 December 2017 – 'Assisted dying developments across Australasia.' This update discusses recent developments in Australia, including the very recent passing of the Voluntary Assisted Dying Bill 2017 in Victoria and the almost simultaneous failure of a similar Bill of the same name in New South Wales. The update also touches on where things are at in New Zealand, particularly in light of our recent change of Government. Over the last few weeks, two Australian states, New South Wales and Victoria, have both debated Bills proposing to legalise assisted dying. On 16 November, the New South Wales Upper House narrowly voted down the Voluntary Assisted Dying Bill 2017 by a margin of a single vote. In contrast, a few days later, the opposite result occurred in Victoria, where, after approximately 100 hours of debate, a Bill with the same name was passed. The Victorian Bill received royal assent on 5 December, which means that a legally assisted dying regime will be implemented in Victoria by mid 2019. https://goo.gl/An6ey9

#### **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.

#### **Distribution**

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

### **Links to Sources**

- 1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
- 2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
- 3. Links often remain active, however, for only a limited period of time.
- 4. Access to a complete article, in some cases, may require a subscription or one-time charge.
- 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.

## **Specialist Publications**

### Systematic review of aged care interventions for older prisoners

AUSTRALASIAN JOURNAL OF AGEING | Online - 6 December 2017 - The current systematic review found no significant effects of aged care interventions in prisons. However, qualitative findings showed aged care interventions to have a beneficial impact on older prisoners when the intervention targeted the specific health and well-being needs of this population, while simultaneously addressing barriers to participation and facilitating engagement among older prisoners. Recommendations arising from this review include targeting aged care interventions in prisons to the unique physical health, mental health, social care and spiritual needs of older prisoners. The review also showed that prison-based interventions should specifically aim to address the isolation and anxiety of older prisoners to ensure engagement with a program. The review findings also centre recommendations on addressing certain barriers to aged care in the prison environment. Importantly, relationships between older prisoners and prison staff need to be cultivated to establish trust and mutual goal setting. Furthermore, aged care interventions should take into account and work within the limitations of the prison environment and prison budget restrictions to ensure sustainability of a program. Finally, review recommendations for efficacious program delivery centre

on intervention legitimacy for engaging both older prisoners and prison staff. Legitimacy will necessarily involve evidence-based interventions and input from health specialists within the aged care field. However, perhaps of equal importance in a prison setting is involving older prisoners and prison staff in the program development process. The review found that involving stakeholders in the development process provided justification for an intervention and bestowed legitimacy on it, while also encouraging engagement. Extract from the authors' conclusions: link to abstract and access to full text options at: <a href="https://goo.gl/THFuwa">https://goo.gl/THFuwa</a>

### Extract from Australasian Journal of Ageing article

Prison hospice services are provided in countries such as the U.S. in an attempt to meet the needs of older prisoners. Nursing home prisons in the U.S. and Germany provide specialised aged care services to prisoners. There are also specialised aged care units in mainstream prisons in the U.K. and Australia which provide suitable facilities for older prisoners. Specialist aged care staff have also been hired to respond to the specific needs of older prisoners.

### Related

- HEALTH AFFAIRS | Online 6 December 2017 'New findings on prison health care highlight the challenges of aging behind bars.' A recent report ... finds that U.S. states nationwide face rising prison health care costs, exacerbated by their aging prison populations. The share of people ages fifty-five and older increased in forty-four states between fiscal years (FYs) 2010 and 2015, and this age group now accounts for more than 10% of the prison population in twenty-five states. In New York State, the overall prison population decreased 10% from FY 2010 to 2015 (that is, from 59,237 people to 53,181 people), yet the number of older adults in New York State prisons grew by 15% during that time rising from 7-9% of the share of people in custody. These aging people in prison experience higher rates of serious and chronic disease than do their younger counterparts and consume more health care. Full text: https://goo.gl/E9pvQx
  - 'Prison Health Care: Costs and Quality,' Pew Charitable Trusts, October 2017. Download/view at: https://goo.gl/ZCzksA

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 November 2017) can be downloaded/viewed at Palliative Care Network-e: https://goo.gl/YLckx6

# The relationships between the combination of person- and organization-related conditions and patients' perceptions of palliative care quality

BMC PALLIATIVE CARE | Online – 6 December 2017 – Little is known about the combination of personand organization- related conditions and the relationships with patients' perspectives of care quality. Such a combination could contribute knowledge reflecting the complexity of clinical practice, and enhance individualized care. Patients [i.e. study participants] scored the care received and the subjective importance as moderate to high. The combination of person- and organization - related conditions revealed that patients with a high sense of coherence, lower age (person – related conditions) and being in a ward with access to and availability of physicians (organization-related condition) might be associated with significantly higher scores for the quality of care received. Gender (women), daily contact with family and friends, and low health-related quality of life (person-related conditions) might be associated with higher scores for subjective importance of the aspects of care quality. Full text: <a href="https://goo.gl/815TH5">https://goo.gl/815TH5</a>

# Changes in older people's care profiles during the last 2 years of life, 1996-1998 and 2011-2013: A retrospective nationwide study in Finland

BMJ OPEN | Online – 1 December 2017 – Most older people continue to live in their homes until the last months of their lives. This pattern of care is in line with current care recommendations, which emphasise the benefits of living in a private home, and care provided in non-institutional settings. Yet, living the most of the last 2 years of life in long-term care settings increased from 1996-1998 to 2011-2013. The reasons behind this development should be studied further. Increasing age at the time of death, and an increase in multi-morbidity, especially dementia, might have contributed to the increase in care use near the time of death. It is, therefore, important to bear in mind that living at home until close to death may present new problems and challenges for the older people themselves as well as for their care providers, especially when those last years and months of life are increasingly lived at a very old age, and with multi-morbidity. The care systems must be prepared for the challenges of more severe disability as well as for longer periods of long-term care as needed at the end of life. Full text: https://goo.gl/XAe9D9

### Withholding and withdrawing life support: Difficult decisions around care at the end of life

CANADIAN JOURNAL OF ANESTHESIA | Online – 30 November 2017 – The Canadian Critical Care Society has released a position paper on withholding and withdrawing life-sustaining treatment (WWLST). The authors' objective was to create a framework for healthcare professionals to help them understand and develop an approach to end-of-life care (EoLC) decision-making in the intensive care unit. EoLC and WWLST are common issues in the ICU, and as the authors have identified in their article, these practices require careful attention to a number of ethical factors and legal precedents as well as to the context of the patient/family and healthcare professionals. This editorial provides additional comments on WWLST and EoLC. Full text: <a href="https://goo.gl/4AUJtt">https://goo.gl/4AUJtt</a>

 Withholding and withdrawing life-sustaining treatment: The Canadian Critical Care Society position paper,' Canadian Journal of Anesthesia, published online 17 November 2017. Access options at: https://goo.gl/q12wJS

### Surprised by benefit in pediatric palliative care research

CANCER NURSING, 2018;41(1):86-87. The field of pediatric palliative care (PC) relies on studied outcomes to foster the foundational knowledge needed to guide best practice and inform interventions. Research allows us opportunities to build or refine knowledge on which to improve current practice. Research may not offer direct benefit to the participant but to future like others. For seriously ill children and their families, clinicians are seeking situations of benefit while protecting against harm. As the benefits

and risks for children and families participating in PC research are largely unknown, most clinicians and review boards focus on the potential for harm. Institutional review boards may be reluctant to approve research for vulnerable populations using a biomedical model to assess harm without equally examining the perceived benefit of social and behavioral research findings. We have witnessed this well-intended focus on hypothetical harm become a fear of potential harm, which translates into a resistance to approve pediatric PC research. This fear-harm cycle impedes research progress in this understudied population. Although steps are put in place to ensure safety and protection, pediatric PC researchers do not currently have a guiding standard to measure burden, minimize harm, or trigger harm-recovery interventions. While consistently preparing to avoid harm, pediatric PC researchers have borne witness to profound benefits in conducting research with pediatric PC patients – including research that relies on hearing the child's voice at the end of life. Benefits range from transparency to transcendence, an opportunity to engage in honesty and to be heard, memory making to legacy building, and symptom management to supportive interventions. Full text: https://goo.gl/zyw7r9

### Related

■ PEDIATRIC BLOOD & CANCER | Online – 8 December 2017 – 'Illness and end-of-life experiences of children with cancer who receive palliative care.' The majority of pediatric palliative oncology patients [i.e., the patient population studied] received experimental therapy (79.4%), with 40.5% enrolled on a phase I trial. Approximately one-third received cancer-directed therapy during the last month of life (35.5%). More than half had at least one intensive care unit hospitalization (51.4%), with this subset demonstrating considerable exposure to mechanical ventilation (44.8%), invasive procedures (20%), and cardiopulmonary resuscitation (12.1%). Of the 122 patients who died in the hospital, 44.3% died in the intensive care unit. Patients with late PC involvement occurring less than 30 days before death had higher odds of dying in the intensive care unit over the home/hospice setting compared to those with earlier PC involvement. Abstract: https://goo.gl/F5otEC

Noted in Media Watch 10 August 2015 (#422, p.13):

■ BMC PALLIATIVE CARE | Online – 4 August 2015 – 'Priorities for global research into children's palliative care: Results of an international Delphi study.' The top five research priorities identified in this study were: 1) Children's understanding of death and dying; 2) Managing pain in children where there is no morphine; 3) Funding; 4) Training; and, 5) Assessment of the WHO two-step analgesic ladder for pain management in children. Information from this study is important for policy makers, educators, advocates, funding agencies, and governments ... [and] ... provides a much needed starting place for the allocation of funds and building research infrastructure. Full text: <a href="https://goo.gl/NB5ppC">https://goo.gl/NB5ppC</a>

### Caregiver anticipatory grief: Phenomenology, assessment and clinical interventions

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 4 December 2017 – Recent literature illustrates the wide scope of the current use of the term anticipatory grief, reflecting caregivers' experiences in different end-of-life (EoL) trajectories. The anticipation of death is the distinctive aspect of anticipatory grief in the pre-death grief continuum, encompassing several progressive losses, past and future. Recently developed assessment instruments capture key aspects of this experience, such as separation anxiety, anticipation of death and future absence of the person, denial and relational losses. Recent findings on prevalence of clinically significant pre-death symptoms in caregivers range from 12.5 to 38.5%. Beyond personal and relational factors, difficult circumstances of EoL care significantly interfere in adjustment to anticipatory grief. Useful therapeutic interventions were identified, such as validation of grief feelings, increased coping and self-care, anticipation of future losses and reframing roles. However, rigorous interventional studies are needed to create guidelines and the manualization of specific therapeutic approaches to caregiver anticipatory grief. Findings suggest that anticipatory grief dynamics in different EoL trajectories should be recognized and adequately assessed. Clinical interventions considered useful to support anticipatory grief caregivers are presented, but further research is needed to verify effectiveness. Abstract: https://goo.gl/C7qFD6

**N.B.** Additional articles on anticipatory grief are noted in the 5 September 2016 and the 16 May 2016 issues of Media Watch (#478, p.19 and #462, pp.6-7, respectively).

# How we say goodbye: Social media, death and the paediatric intensive care unit



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(6):248-250. The massive expansion in the use of various social networking websites and apps over the past decade has led to a world in which

adolescents and many parents use these types of media intensively. The authors discuss the implications of the rise in use of social media for the paediatric intensive care unit. Key points: the ability to generate user content and immediately publish online may influence relationships between patients and healthcare staff; many patients and parents derive psychological and emotional reassurance from their interaction with social networking websites and apps; the critical care unit represents a technology dominated medical specialty, which is now seeing the impact of social media on patient staff interactions; and, hospitals may begin to address the impact of social media on clinical practice, in the form of official codes of behaviour, patient advocacy liaison between staff and families, and provision of counseling for staff and families affected by these issues.



Access to the European Journal of Palliative Care requires a subscription. November/December issue contents page: https://goo.gl/hwusd4

## Patient journeys through the palliative care system in Germany



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(6):251-255. Over the last three decades, Germany has built up a comprehensive palliative care (PC) system with various types of services in the ambulatory and the inpatient sector. The aim of this study was to visualise the typical pathway of a PC patient according to relevant laws and medical rec-

ommendations, and subsequently calculate transition probabilities between PC services to test whether the theoretically plausible pathways are realised in practice. Descriptive analysis and transition probabilities suggest that the intended sequence of PC service usage is in accordance with underlying laws and medical recommendations. Hospital PC units are often the first point of contact with PC, indicating that hospitals play an important role as "information transmitters." PC services are typically used in the last 1-3 months of life, suggesting that knowledge of PC is not yet widespread enough, as PC could benefit patients (and relatives) much earlier.

#### Related

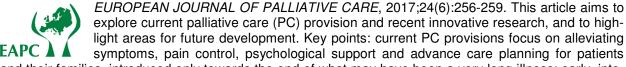
CENTRAL EUROPEAN JOURNAL OF NURSING AND MIDWIFERY, 2017;8(4):723-730. 'Family caregiver satisfaction with home-based palliative care services in Northern Rhine-Westphalia, Germany.' The authors found high satisfaction within the patient sample studied. There was high satisfaction with how the services respected the dignity of families, and how they provided comfort to patients. Satisfaction was lower with regard to information about patients. High or low satisfaction with palliative care tells little about the quality of services. Abstract: https://goo.gl/MGL737



### 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.

### Innovation in palliative care: What's next?



and their families, introduced only towards the end of what may have been a very long illness; early, integrated PC may have benefits, including increased patient satisfaction and quality of life, care more consistent with patient preferences, reduced depression and increased length of survival; a precise time for the integration of PV into patients' pre-existing care has not yet been determined; this is a potential area for future studies to investigate; the future of PC provision lies in empowering patients to make more decisions, more readily, at the end of life (EoL); this could be achieved through earlier and increased frequency of access to PC services (for example, through a joint oncology and PC clinic service): and, routine integrated PC will hopefully diminish the stigma associated with PC, enabling more patients to feel able to use hospice services without fearing that they are approaching the EoL, which will require a change in attitudes towards PC among healthcare professionals as well as the public and could be achieved over time through widespread education.

Noted in Media Watch 4 December 2017 (#541, p.10):

- THE HIPPOCRATIC POST | Online 28 November 2017 'Does research improve clinical care?' The volume of research in palliative care has increased since Cicely Saunders' pioneering studies, but what do we know about its value? What constitutes the wrong research question? Aren't all research questions of value? If a question is asked to which there is already a reliable answer then repeating this study is of little benefit to patients. If a research question is considered of little importance to patient and families resources would be better spent elsewhere. Full text: https://goo.gl/kzqVsR
  - 'Reducing waste from incomplete or unusable reports of biomedical research,' The Lancet, 2014; 383(9913):267-276. Summary: <a href="https://goo.gl/yHnfoD">https://goo.gl/yHnfoD</a>

Noted in Media Watch 20 November 2017 (#539, p.9):

- ANNALS OF INTERNAL MEDICINE | Online 14 November 2017 'A research agenda for high-value palliative care.' Because demand has quickly outstripped the supply of palliative care (PC) specialists, the field's ability to sustainably provide high-value care is paradoxically threatened by its own success. The authors propose a research agenda organized around five key questions on the optimal organization and allocation of limited resources in specialty PC to close the gap between the workforce and patient need. Abstract: https://goo.gl/ZbDzx2
  - N.B. Additional articles on research priorities in palliative care are noted in this issue of Media Watch.

### Psychological ideas in palliative care: Behaviour change



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(6):260-265. This article is the sixth in the journal's series 'Psychology in palliative practice.' When we think of behaviour change in a healthcare context, we typically think of interventions at an early point in a disease course, such as smoking cessation programmes to prevent development of can-

cers, or weight loss programmes. There is little written at all about behaviour change in palliative care settings. But many of the most challenging cases encountered in these settings – such as non-compliance with medicines, persistent reassurance seeking and strain in family relationships – ultimately boil down to understanding and adjusting the relationship between behaviour and its reinforcers.

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Back Issues of Media Watch <a href="http://goo.gl/frPgZ5">http://goo.gl/frPgZ5</a>

#### Related

• AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 December 2017 – 'Palliative care providers' practices surrounding psychological distress screening and treatment: A national survey.' Providers (i.e., survey respondents) reported that they encounter psychological distress regularly in their practice and that they screen for distress using multiple methods. When psychological distress is detected, providers reported referring patients to an average of three different providers, most frequently a social worker or chaplain on the palliative care (PC) team. This study revealed significant variability and redundancy in how PC teams currently manage psychological distress. Abstract: <a href="https://goo.gl/juA5tX">https://goo.gl/juA5tX</a>

# Developing volunteers to support end-of-life patients and their carers: A study of a volunteer training programme



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(6):277-282. Hospices have a long history of using volunteers in a wide variety of roles to supplement the paid workforce. However, the kinds of tasks that volunteers in hospices are now undertaking are changing. It is anticipated that with help from volunteers, people receiving palliative care

(PC) will have a better quality experience and use their health services more appropriately. Hospice volunteers in the U.K. can be divided into two categories, patient-facing and support. Patient-facing volunteers are in direct contact with hospice patients (in- or outpatients or receiving PC at home) and their families. This article presents an innovative, collaborative approach between five hospices in south London that planned, developed and provided a common training programme for volunteers in patient-facing roles, and an evaluation research study that was undertaken into that training programme.

Noted in Media Watch 13 November 2017 (#538, p.16):

■ PROGRESS IN PALLIATIVE CARE | Online – 5 November 2017 – ""A strange kind of balance": Inpatient hospice volunteers' views on role preparation and training.' There is a paucity of research on the training needs of hospice volunteers. In the U.K., there have been calls for the development of a core curriculum for hospice volunteers, but debate exists around the potential for unnecessary "professionalization" of volunteers, diluting their unique contribution. This qualitative, focus group study explores the views of U.K. inpatient hospice volunteers regarding initial training for role preparation. Abstract: https://goo.gl/VsMf55

**N.B.** Additional articles on hospice and palliative care volunteers are noted in the 20 March 2017 issue of Media Watch (#504, p.6).

# Characterizing the role of U.S. surgeons in the provision of palliative care: A systematic review and mixed-methods meta-synthesis

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 5 December 2017 – A total of 2,589 abstracts were identified and screened, and 35 articles (26 quantitative and nine qualitative) fulfilled criteria for full review. Among these, 17 articles explored practice and attitudes of surgeons regarding palliative and end-of-life care, 11 articles assessed training in palliative care (PC), five characterized surgical decision-making, one described behaviors of surgeons caring for seriously-ill and dying patients, and one explicitly identified barriers to use of PC. Four major themes across studies affected receipt of PC for surgical patients: 1) Surgeon experience and knowledge; 2) Surgeons' attitudes; 3) Surgeons' preferences and decision-making for treatment; and, 4) Perceived barriers. Among the articles reviewed, surgeons overall demonstrated insight into the benefits of PC, but reported limited knowledge and comfort as well as a multitude of challenges to introducing PC to their patients. These findings indicate a need for wider implementation of strategies that allow optimal integration of PC with surgical decision-making. **Abstract:** https://goo.gl/L7i7wa

**N.B.** Additional articles on palliative care in surgery are noted in the 8 May 2017 issue of Media Watch (#511, p.6).

### What accounts for disparities in the use of palliative stroke care? It may not be what you think

NEUROLOGY TODAY, 2017;17(23):14-15. Why do black and other ethnic minorities receive less palliative care (PC) after ischemic stroke and intracerebral hemorrhage? Past studies have suggested that the attitudes of the patients themselves – their religious beliefs and lack of knowledge or trust in PC solutions – drive their preferences for lifesaving options in critical care scenarios. But a new analysis in a recent issue of *Critical Care Medicine* suggests that it might be the systems in place in hospitals serving minority populations – and not the belief systems of individual patients – that account for these racial disparities in care. Analysis of data from the nationwide inpatient sample confirmed that ethnic minorities who had a stroke were less likely to receive PC than whites. But it also showed that all patients with stroke – regardless of racial/ethnic identity – were less likely to receive PC if they were cared for in largely minority-serving hospitals. Full text of expert commentary: <a href="https://goo.gl/SX82Md">https://goo.gl/SX82Md</a>

'Racial differences in palliative care use after stroke in majority-white, minority-serving, and racially integrated U.S. hospitals,' *Critical Care Medicine*, 2017;45(12):2046-2054 (first published online 14 October 2017). Abstract: <a href="https://goo.gl/NujFLJ">https://goo.gl/NujFLJ</a>

**N.B.** 'Palliative care and cardiovascular disease and stroke: A policy statement from the American Heart Association and the American Stroke Association,' *Circulation*, 2016;134(11):e198-e225. [Noted in the 18 September 2017 issue of Media Watch (#530, p.2)] **Abstract:** https://goo.gl/2u9mE2

### An employer health incentive plan for advance care planning and goal-aligned care

POPULATION HEALTH MANAGEMENT | Online – 6 December 2017 – One strategy to promote work-force well-being has been health incentive plans, in which a company's insured employees are offered compensation for completing a particular health-related activity. In 2015, Providence Health & Services adopted an advance care planning (ACP) activity as a 2015-2016 health incentive option. More than 51,000 employees and their insured relatives chose the ACP incentive option. More than 80% rated the experience as helpful or very helpful. A high proportion (95%) of employees responded that they had someone they trusted who could make medical care decisions for them, yet only 23% had completed an advance directive (AD), and even fewer (11%) had shared the document with their health care provider. The most common reason given for not completing an AD was that health care providers had never asked about it. These findings suggest that an insured employee incentive plan can encourage ACP consistent with the health care organizations' values and strategic priorities. **Abstract:** https://goo.gl/eiiZSU

### **Emergency medical services provider experiences of hospice care**

PREHOSPITAL EMERGENCY CARE | Online – 4 December 2017 – Growing numbers of emergency medical services (EMS) providers respond to patients who receive hospice care. Survey respondents included 86 (47.3%) EMTs with intermediate and advanced training, and 96 (52.7%) paramedics. There were no significant differences between EMTs and paramedics in their knowledge of the care of these patients, nor were there significant differences between those with 0-5 and 5-plus years of experience. Furthermore, 53 (29.1%) EMS providers reported receiving formal education on the care of hospice patients. A total of 36% felt that patients in hospice care required a DNR order. In EMS providers' openended responses on challenges in responding to the care needs of hospice patients, common themes were family-related challenges and the need for more education. EMS providers have expressed a need for a formal curriculum on the care of the patient receiving hospice. Abstract: <a href="https://goo.gl/d4kapN">https://goo.gl/d4kapN</a>

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# **Palliative Care Network**

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

Noted in Media Watch 9 November 2015 (#435, p.9):

AUSTRALASIAN JOURNAL OF PARAMEDICINE, 2015;12(5):Article #3. 'Paramedics' perceptions and educational needs with respect to palliative care.' Paramedics [i.e., survey respondents] have a sound grasp of some important aspects of palliative care (PC), including symptom control and the holistic nature of the palliative approach. They did, however, tend to equate PC with care occurring in the terminal phase and saw it as being particularly applied to cancer diagnoses. Paramedic PC educational efforts should be focused on: 1) Ethical issues; 2) End-of-life communication; 3) Increasing understanding of the common causes of death; and, 4) Education regarding those illnesses where a palliative approach might be beneficial. Abstract: <a href="https://goo.gl/MgXvRk">https://goo.gl/MgXvRk</a>

# Deaths in France: Characteristics, place of death, hospitalisations and use of palliative care during the year before death

REVUE D'ÉPIDÉMIOLOGIE ET DE SANTÉ PUBLIQUE | Online – 2 December 2017 – Only limited data are available concerning the diseases managed and the hospital pathway before death. A total of 347,253 people were included (61% of all deaths in France in 2013). The mean age of death was 77 years. Diseases managed before death were cardiovascular/neurovascular diseases (56%), cancers (42%), neurological and degenerative diseases (25%), diabetes (21%) and chronic respiratory diseases (20%). Deaths occurred in hospital in 60% of cases: 51% in acute wards, 6% in rehabilitation units, 3% in hospital at home, and 13% in nursing homes. During the year preceding death, 84% of people were hospitalised at least once and 29% received hospice palliative care (HPC). People receiving HPC more often died in hospital than people not receiving HPC (69% vs. 44%). Health administrative data ... can refine our knowledge of the care pathway prior to death and of the use of HPC and can be useful to evaluate the new governmental palliative care plan recently deployed in France. **Abstract:** <a href="https://goo.gl/xKJemf">https://goo.gl/xKJemf</a>

**N.B.** French language article.

Noted in Media Watch 4 July 2016 (#469, p.15):

■ MÉDECINE PALLIATIVE | Online – 27 June 2016 – 'Palliative care in hospital-at-home services in France: Nationwide study using administrative data.' Hospital-at-home services increased the provision of palliative care (PC) between 2008 and 2014 (+61% increase in the number of home-based hospitalizations, accounting for 28,000 patients in 2014). PC now accounts for 23.6% of the total number of days of hospitalization. In 2014, almost 18,000 individuals died while being hospitalized at home (including 13,700 during a PC stay), the proportion of deaths in overall number of discharges rising from 7.2% in 2008 to 10.2% in 2014. However, the authors found considerable variation in the development of PC in hospital-at-home services across counties. Abstract: <a href="http://goo.gl/APoJon">http://goo.gl/APoJon</a>

N.B. French language article.

# A novel family dignity intervention for enhancing and informing holistic palliative care in Asia: study protocol for a randomized controlled trial

TRIALS | Online – 4 December 2017 – The lack of a holistic approach to palliative care (PC) can lead to a fractured sense of dignity at the end of life, resulting in depression, hopelessness, feelings of being a burden to others, and the loss of the will to live among terminally ill patients. Building on the clinical foundation of dignity therapy, together with the empirical understanding of dignity-related concerns of Asian families facing terminal illness, a novel family dignity intervention (FDI) has been developed for Asian PC. FDI comprises a recorded interview with a patient and their primary family caregiver, which is transcribed, edited into a legacy document, and returned to the dyads for sharing with the rest of the patient's family. This first-of-its-kind study develops and tests an evidence-based, family driven, psycho-socio-spiritual intervention for enhancing dignity and wellbeing among Asian patients and families facing mortality. It addresses a critical gap in the provision of holistic PC. The expected outcomes will contribute to advancements in both theories and practices of PC for Singapore and its neighboring regions while serving to inform similar developments in other Asian communities. Full text: https://goo.gl/tJXoAQ

### End-of-life care in Taiwan

# The Hospice Information System and its association with the congruence between the preferred and actual place of death

TZU CHI MEDICAL JOURNAL, 2017;29(4):213-217. A Hospice Information System (HIS) developed in eastern Taiwan in 2012 aimed to improve the quality of hospice care through an integrated system that provided telemetry-based vital sign records, online 24/7 consultations, online video interviews, and online health educations. The purpose of this study was to explore the congruence between the preferred and actual place of death (PoD) among patients who received HIS services. In total, the authors enrolled 481 patients who received HIS services and died. Of them, 444 (92.3%) died at their preferred PoD. Patients who preferred an inpatient hospice as their PoD had higher achievement rate than those who wanted a home death. High-intensity HIS utilization was associated with a higher likelihood of home death than low-intensity HIS utilization. Patients living in areas distant from the medical center had lower achievement of home death than those living in local areas. **Full text:** https://goo.gl/W6t7Yw

**N.B.** English language article. Additional articles on end-of-life care in Taiwan are noted in the 23 October 2017 issue of Media Watch (#535, pp.8-9).

### Assisted (or facilitated) death

Representative sample of recent journal articles:

BMC MEDICAL ETHICS | Online – 7 December 2017 – 'Attitudes towards assisted suicide and euthanasia among care-dependent older adults (50+) in Austria: The role of socio-demographics, religiosity, physical illness, psychological distress, and social isolation.' Care-dependency constitutes an important issue with regard to the approval of end-of-life decisions, yet attitudes towards assisted suicide and euthanasia are understudied among care-dependent older adults. A nationwide cross-sectional survey among older care allowance recipients (50+) in private households in Austria was conducted in 2016. About a quarter of the sampled care-dependent older adults approved of the availability of assisted suicide and euthanasia respectively indicated the will to (hypothetically) make use of assisted suicide or euthanasia. Attitudes towards assisted suicide were most favourable among care-dependent older adults living in urban areas, those who did not trust physicians, those who reported active suicide ideation, and individuals with a strong fear of dying. With regard to euthanasia, living alone, religiosity and fear of dying were the central determinants of acceptance. Full text: https://goo.gl/4FLB9S

## **Journal Watch**

### Authorship and citation manipulation in academic research

PLOS ONE | Online – 6 December 2017 – Some scholars add authors to their research papers or grant proposals even when those individuals contribute nothing to the research effort. Some journal editors coerce authors to add citations that are not pertinent to their work and some authors pad their reference lists with superfluous citations. How prevalent are these types of manipulation, why do scholars stoop to such practices, and who among us is most susceptible to such ethical lapses? This study builds a framework around how intense competition for limited journal space and research funding can encourage manipulation and then uses that framework to develop hypotheses about who manipulates and why they do so. The authors test those hypotheses using data from over 12,000 responses to a series of surveys sent to more than 110,000 scholars from eighteen different disciplines spread across science, engineering, social science, business, and health care. They find widespread misattribution in publications and in research proposals with significant variation by academic rank, discipline, sex, publication history, co-authors, etc. Even though the majority of scholars disapprove of such tactics, many feel pressured to make such additions while others suggest that it is just the way the game is played. The findings suggest that certain changes in the review process might help to stem this ethical decline, but progress could be slow. Full text: https://goo.gl/7AN8mr

### **Media Watch: Online**

#### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/3oecYD

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

PALLIATIVE CARE NETWORK-e: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

#### Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/IXO4mD

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

### Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD

[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: <a href="https://goo.gl/ds5wYC">https://goo.gl/ds5wYC</a> [Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

### **Europe**



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://goo.gl/o7kN3W

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HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1l9K

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

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