# 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

Integration of palliative care into standard oncology care: Scroll down to <u>Specialist Publications</u> for a selection of articles, beginning on p.11, published in the *Journal of Oncology Practice*.

## Canada

## He's waited for a hospice bed for months. But someone basically has to die first

BRITISH COLUMBIA | Global News TV - 25 August 2017 - A Vancouver Island family is speaking out about a painful wait for hospice care. Tracey Stodgell said David Matthews, her father, is terminally ill. He was diagnosed with Leukemia in April and the family has been waiting months for him to access a hospice bed. The other alternative, the family ... was told, is the hospital emergency room. The situation is frustrating and difficult, and they feel helpless. The average wait for a hospice bed varies based on need and availability, Vancouver Island Health Authority said. "There is an admission panel that reviews admissions to ensure appropriate individuals and families with the most urgent needs for care are given priority," the authority said in a statement to Global News. "It is important to

note that end-of-life care is about much more than beds. It includes a range of primary, enhanced and complex end-of-life programs and services." "There is an admission panel that reviews admissions to ensure appropriate individuals and families with the most urgent needs for care are given priority," the authority said in a statement to Global News. https://goo.gl/xa5uoo

## **Specialist Publications**

'A survey of Canadian nephrologists assessing prognostication in end-stage renal disease' (p.8), in Canadian Journal of Kidney Health & Disease.

#### Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ THE GLOBE & MAIL | Online - 23 August 2017 - 'Canadian Medical Association poll finds rising support for medically assisted death.' A straw poll conducted at the Canadian Medical Association (CMA) annual meeting found that 83% of delegates supported allowing "advance directives" - meaning, for example, that people with dementia could, while they are still competent, decide they want an assisted death at a later time. The informal poll of the 600 delegates also found that 67% backed the idea of "mature minors" being allowed to access assisted death. Physicians, however, were far less enthusiastic about allowing assisted death for patients whose sole problem is mental illness: Only 51% backed that idea. Similar CMA straw polls showed that, in 2013, only 34% of doctors supported assisted dying legislation; that rose to 45% in 2014. https://goo.gl/6yejsg

## U.S.A.

#### Palliative care: Underutilized treatments for lowans

IOWA | The De Moines Register - 25 August 2017 - Increasing quality while reducing costs is a major public health challenge facing our nation's health-care system. For seriously or terminally ill patients, palliative care (PC) is a rapidly growing medical field aimed at improving the quality of life for both patients and family members. This type of care focuses on providing relief from the symptoms and stresses of a serious illness. It is appropriate at any age and at any stage in a serious illness, and can be provided along with curative treatment. Palliative and hospice care differ from one another - hospice is a sub-set of PC. PC does not have any eligibility restrictions. Whereas, with hospice, the physician must certify that the individual is unlikely to live more than six months and that all curative treatment must cease. The misconception that palliative and hospice care are the same thing has made PC a sensitive and often-avoided subject with patients and providers alike. While PC may include hospice care, even without it, PC can be incredibly helpful to patients suffering with a severe or life-limiting illness. Because of the confusion between palliative and hospice care, PC services are often unavailable and underutilized. These two barriers — lack of coverage and reluctance to refer — have contributed to an inconsistent patient experience across lowa. https://goo.gl/FrwTnY

#### **Specialist Publications**

'Variation in end-of-life care is an open invitation for Accountable Care Organization innovation' (p.9), in *Health Affairs*.

#### Hospice live discharges: Some perspective

THE NATIONAL LAW REVIEW | Online – 23 August 2017 – News outlets have noted that hospices discharge, on average, 1 in 5 patients alive. The presumptive and easy explanation, one that fits political assumptions, is profit motive: for profit hospices admit unwitting patients, earn fees, then discharge them alive. The truth is that assessing when someone will pass away is among the most complex medical determinations. It's not easy, it's not an exact science. The media, and MEDPac also, ignore longstanding journal articles that detail in scientific terms the conundrum faced by hospices. Specifically, for non-cancer terminal illnesses, like dementia, heart disease, lung disease, and kidney disease, objective measurements are not available to allow us to fully separate those that will pass away in six months from those that won't. The findings present a basic choice: If we wish to provide the option of hospice for even a majority of those that will pass away in the next six months from non-cancer terminal illnesses, then we must set criteria that will in turn allow hospice for perhaps 2 or 3 additional patients who won't pass away in that same time. If instead we want to admit to hospice only those that will pass away in the next six months, then at most 1 in 10 of the patients that actually will pass away will have a hospice option. <a href="https://goo.gl/5eZgTC">https://goo.gl/5eZgTC</a>

1. 'Nearly 1 in 5 hospice patients discharged while still alive, National Public Radio, broadcast 11 August 2017. [Noted in Media Watch 14 August 2017 (#525, p.2); additional articles on hospice discharge or disenrollment are noted in this issue of the weekly report.] https://goo.gl/xw3Wjr

## Need for caregiving doubles as end of life nears

UNITED PRESS INTERNATIONAL | Online – 22 August 2017 – Reliance on caregivers doubles as people near death, and half of those caregivers – typically unpaid family members – report having no time for themselves, a new study indicates. The research used a nationally representative sample of about 2,400 older adults in the U.S. The study authors found that caregivers provided nearly twice the number of hours of help each week to dying individuals than to those not at the end of life (EoL). "We were certainly aware when dealing with EoL care that families are mostly involved, but we couldn't quantify that prior to

this research," said study author Dr. Katherine Ornstein. She's an assistant professor of geriatrics and palliative medicine at the Icahn School of Medicine at Mount Sinai in New York City. More than 34 million Americans provided unpaid care to an adult aged 50 or older in the past 12 months, according to 2015 figures from the National Alliance for Caregiving and American Association for Retired Persons. Most caregivers are female. https://goo.gl/CjJjMP

- 'A national profile of end-of-life caregiving in the U.S.,' Heath Affairs, 2017;36(7):1184-1192. Abstract: https://goo.gl/ZjCsha
  - **N.B.** The focus of this issue of *Health Affairs* is on advance illness and end-of-life care. [Noted in Media Watch 10 July 2017 (#520, p.10)] Journal contents page: <a href="https://goo.gl/jebK3j">https://goo.gl/jebK3j</a>
- 2. 'Caregiving in the U.S. 2015,' National Alliance for Caregiving & American Association for Retired Persons. [Noted in Media Watch 26 October 2015 (#433, p.13)] https://goo.gl/N98Y6k

## Despite advance directive, dementia patient denied last wish, says spouse

OREGON | Kaiser Health News – 21 August 2017 – A southern Oregon case underscores the complexity surrounding the use of advance directives for people with Alzheimer's disease and other dementias. These directives generally allow named agents the power to withdraw artificial hydration and nutrition in the form of feeding tubes, for instance. But when that same nourishment is offered by hand, several states, including Oregon, draw a line, said Thaddeus Mason Pope, director of the Health Law Institute at Hamline University in St. Paul, Minnesota, and an expert on end-of-life (EoL) law. Across the U.S., the more than 5 million people living with

dementia are typically encouraged to put their EoL wishes into writing early and to pick a trusted person to carry them out, said Beth Kallmyer, vice president of constituent services for the Alzheimer's Association. That's no guarantee, however, that those requests can – or will – be honored. https://goo.gl/7JTx5S

#### **Specialist Publications**

'Advance directives and the descendant argument' (p.10), in *HEC Forum*.

Noted in Media Watch 21 August 2017 (#526, p.15):

MEDICAL LAW REVIEW | Online – 16 August 2017 – 'Protecting me from my directive: Ensuring appropriate safeguards for advance directives in dementia. Advance directives provide an important means of empowerment. Upholding directives in the context of dementia, however, raises extra challenges, given the potential for the directive to conflict with an assessment of what is in the person's current best interests. Abstract: <a href="https://goo.gl/HJE4vS">https://goo.gl/HJE4vS</a>

## Study: Nearly half of cancer patients can't answer basic questions about their disease

PENNSYLVANIA | Lancaster Online – 21 August 2017 – Nearly half of cancer patients cannot correctly answer basic questions about their disease, according to a local study that experts say has national implications. The medical community uses a four-stage terminology to describe how advanced cancer is at first diagnosis, with Stage 4 indicating the most advanced disease. Of 208 patients surveyed in 2014 ... 49% got the stage of the cancer wrong. And when they were asked the status of their disease – cancerfree, in remission or active cancer – only two-thirds answered correctly. "It has been well documented that patients with advanced cancer are more likely to choose aggressive end-of-life care when they have a poor understanding of their illness," said the study, which was published recently by the American Society of Clinical Oncology. "This raises significant concerns regarding the informed consent process and our ability to provide care that truly aligns with patient preferences and goals of care." <a href="https://goo.gl/fHmy6U">https://goo.gl/fHmy6U</a>

 'Illness understanding of oncology patients in a community-based cancer institute,' Journal of Clinical Oncology, published online 5 July 2017. Abstract: <a href="https://goo.gl/CgBhg5">https://goo.gl/CgBhg5</a>

## Dying at home in pain doesn't keep relatives from stealing the pills

THE WASHINGTON POST | Online – 21 August 2017 – As more people die at home on hospice, some of the addictive drugs they are prescribed are ending up in the wrong hands. Hospices have largely been exempt from crackdowns in many states on opioid prescription because dying people may need high doses of opioids. But as the opioid epidemic continues, some experts say hospices aren't doing enough to identify families and staff members who might be stealing pills. And now, amid urgent cries for action over rising overdose deaths, several states have passed laws giving hospice staff the power to destroy leftover pills after patients die. Leslie Blackhall, head of palliative medicine at the University of Virginia Health System's palliative care clinic, sounded the alarm about drug diversion in 2013, when she found that most of the 23 Virginia hospices she surveyed didn't have mandatory training and policies on the misuse and theft of drugs. Her study spurred Virginia's hospice association to create guidelines encouraging its members to assess the risk of misuse, and it prompted national discussion among hospice experts. https://goo.gl/LPxhWF

'Risk Evaluation & Mitigation Tool-Kit: Strategies to Promote the Safe Use of Opioids,' Virginia Association for Hospices & Palliative Care. Association website (scroll down to 'Risk Evaluation & Mitigation Tool-Kit): https://goo.gl/ntPm8s

Noted in Media Watch 29 May 2017 (#514, p.11):

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2017;19(3):256-260. 'Hospice-appropriate universal precautions for opioid safety.' Universal precautions for opioid safety is one approach to managing the epidemic of prescription pain medication misuse that has been used in pain clinics, primary care practices, and in some hospices. In this project, a set of hospice-appropriate universal precautions was designed, drawing on hospice nursing strengths, and implemented in a mid-size hospice agency. Abstract: <a href="https://goo.gl/7Wg1TE">https://goo.gl/7Wg1TE</a>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ CALIFORNIA | The Los Angeles Times – 21 August 2017 – 'There's an unforeseen benefit to California's physician-assisted death law.' Many healthcare systems designed protocols for screening people who say they're interested in physician-assisted death, including some that were meant to dissuade patients from taking up the option. But physicians across the state say the conversations that health workers are having with patients are leading to patients' fears and needs around dying being addressed better than ever before. They say the law has improved medical care for sick patients, even those who don't take advantage of it. The health workers ask patients a variety of questions: what scares them, how they're feeling, what they're worried about, what defines their quality of life. Sometimes doctors end up adjusting patients' medicines or treatments because patients hadn't before expressed how much pain they were in. Some patients decide to go on hospice earlier than they would have otherwise. <a href="https://goo.gl/gesxpj">https://goo.gl/gesxpj</a>

## 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>

## International

#### End-of-life care in Belgium

### Why teens need to understand care plans for dying parents

BELGIUM | Reuters – 25 August 2017 – When children lose a parent during adolescence, their mental health as young adults may depend on how comfortable they were with the treatment and support provided at the end of their parents' lives, a recent study suggests. To understand the lasting psychological impact of the death of a parent during adolescence, researchers surveyed young adults who had lost a parent to cancer six to nine years earlier, when they were 13 to 16 years old. Overall, 105 of the 593 young adults (18%) said they had little or no trust in the care provided during the final week of the parent's life. Compared to the participants who were satisfied with the final week of care, those who were unhappy were more than twice as likely to suffer from mental health issues like depression, anxiety and eating disorders. https://goo.gl/nV4bqS

 'Distrust in the end-of-life care provided to a parent and long-term negative outcomes among bereaved adolescents: A population-based survey study,' *Journal of Clinical Oncology*, published online 8 August 2017. [Noted in Media Watch 14 August 2017 (#525, p.8)] Abstract: <a href="https://goo.gl/zNxmK3">https://goo.gl/zNxmK3</a>

#### Elder care in Ireland

### Study: Patients' hearing loss may mean poorer medical care

IRELAND | United Press International – 24 August 2017 – Many seniors may not hear everything their doctors tell them, new research suggests, and that could raise the risk of medical errors. In our study of 100 patients 60 and older, 43 reported mishearing a doctor or nurse in an inpatient or community health care setting, lending vulnerability to unintended error, said researcher Simon Smith, from the University College Cork School of Medicine, in Ireland. Earlier research has found improved communication between doctors, nurses and families could prevent 36% of medical errors. The problem is not just a matter of doctors speaking louder. The ability to separate speech from background noise is more intricate than volume alone, he explained. Often hearing tests don't capture the complexity of how patients process medical information, and hearing aids may not be the answer, Smith said. https://goo.gl/kd4JCG

'Age-related hearing loss and communication breakdown in the clinical setting,' JAMA Otolaryngology

 Head & Neck Surgery,' published online 24 August 2017. Abstract: <a href="https://goo.gl/QLrYfD">https://goo.gl/QLrYfD</a>

Noted in Media Watch 1 May 2017 (#510, p.13):

■ JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 24 April 2017 – 'Studies of physician-patient communication with older patients: How often is hearing loss considered? A systematic literature review.' Hearing loss is prevalent in the geriatric population: one-quarter of adults aged 60-69 and 80% of adults aged 80 years and older have bilateral disabling loss. Only about one in five adults with hearing loss wears a hearing aid, leaving many vulnerable to poor communication with healthcare providers. Abstract: <a href="https://goo.gl/5NZoJM">https://goo.gl/5NZoJM</a>

N.B. Additional articles on hearing loss in the context of end-of-life care are noted in this issue of Media Watch.

#### End-of-life care in China

#### Beijing hospital's hospice pilot struggles for cash, cultural acceptance

CHINA | The Global Times (Beijing) – 21 August 2017 – Every patient who wants to live out what remains of their life in the hospice ward of Beijing Haidian Hospital first needs to get their relatives to sign a document saying that the patient doesn't want doctors to try to cure them any more and that they do not want

to be resuscitated. "This is to guarantee that the patients can have a less painful and dignified death," said Qin Yuan, the oncologist at the hospital who runs a hospice, or palliative care (PC), ward. The hospital started offering hospice services in March, one month after the country's top health authorities called for such care to be promoted nationwide. Since then, its six beds have been home to over 60 terminally ill patients. Though demand for such care is huge, there have been difficulties in introducing this concept in terms of funding, policy support and cultural acceptance. The People's Daily reported in 2016 that some 2.7 million people die of cancer in China annually and they generally spend more than 70% of their total savings on treatment. After the national health authorities made their announcement in February, Beijing announced that it would have more than 10 hospitals pilot PC wards. Chinese society traditionally teaches children to show filial piety, so people worry about how they will be judged for putting their parents in a hospice instead of taking care of them themselves. https://goo.gl/YGqYZL

#### Related

■ CHINA | The South China Morning Post (Hong Kong) – 21 August 2017 – 'Hospice and palliative care services in Hong Kong: How to access them, and why we need to talk more openly about death.' With rising cancer incidence and a growing elderly population – creating more cases of dementia, chronic illness, poverty, loneliness and despair – end-of-life (EoL) care such as pain management and spiritual counselling is in increasing demand in Hong Kong. Such support, though, is not always easy to access. Currently 16 hospitals under Hong Kong's Hospital Authority provide EoL, palliative or hospice care services, with a total of about 360 beds. <a href="https://goo.gl/UG5BPS">https://goo.gl/UG5BPS</a>

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

## Delivering high quality end-of-life care for people who have a learning disability

U.K. (England) | National Health Service - 16 August 2017 - Under each "ambition" those commissioning, providing or delivering care to people with a learning disability at the end of their lives will find "top tips," resources and good practice examples to support the achievement of each ambition for people with a learning disability. It is important to view all people holistically when providing end of life care (EoLC). People with a learning disability, like other members of society, will have a range of characteristics that may inform their needs and expectations in relation to EoLC. For example, expectations about EoLC may be shaped by someone's ethnicity, faith, values and/or other beliefs. It is important not to make assumptions about the care the person needs because of their learning disability

diagnosis. Rather the aim should be to effectively engage with individuals, their families and carers to ascertain their individual needs, expectations and wishes. https://goo.gl/WbSjJm

#### **Specialist Publications**

'Paediatric palliative care and intellectual disability: A unique context' (p.10), Journal of Applied Research in Intellectual Disabilities.

'Supporting end-of-life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability' (p.10), in *Journal of Applied Research in Intellectual Disabilities*.

'Ambitions for Palliative & End-of-Life Care: A National Framework for Local Action 2015-2020,' National Palliative & End-of-Life Care Partnership, September 2015. [Noted in Media Watch 14 September 2015 (#427, p.14)] <a href="http://goo.gl/1cxkfe">http://goo.gl/1cxkfe</a>

#### Related

AUSTRALIA | Australian Broadcasting Corporation – 23 August 2017 – 'Gap in palliative care for Australians with a disability.' Around one in five Australians live with a disability – and like the rest of the ageing population, they'll require end of life care when they become ill. But close attention and understanding of the palliative care needs of disabled people is sorely lacking. This has left a gap between the type of care received by those with a disability and those without. So, what can be done? https://goo.gl/EQ6FVw

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

■ INDIA | NDTV (New Delhi) – 24 August 2017 – 'Right to terminate life is part of right to liberty, says Supreme Court.' The right to die is part of the right to liberty enshrined in the constitution, the Supreme Court indicated as part of its historic judgment on the Right to Privacy. In its comprehensive description of what constitutes privacy, the court said it was about an individual's freedom to make personal choices in life. The right to privacy, the judges said, "safeguards individual autonomy and recognises the ability of the individual to control vital aspects of his or her life. Personal choices governing a way of life are intrinsic to privacy." These choices, the court indicated, can even involve death. "An individual's right to refuse life-prolonging medical treatment or terminate his life is another freedom which fall within the zone of the right of privacy," the court said. https://goo.gl/6i8PEc

## **Specialist Publications**

Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data

ALZHEIMER'S & DEMENTIA | Online – 21 August 2017 – Emergency department (ED) attendance among people with dementia in their last year of life is common and is associated with demographic, illness-related and environmental factors. The strong association between ED attendance and environmental factors is of particular importance given the potentially modifiable nature of these. Care home residence was found to mitigate against ED attendance. In light of the dual pressures of a projected increase in prevalence of dementia and a loss of care home beds in some parts of England, investing in care home (or similar) capacity is urgently needed to avoid unnecessary pressure on emergency care. Although the proportion of people with dementia dying in hospitals has fallen, the authors' data show that ED attendance in the last year of life follows the opposite trend. They recommend that policy makers consider a broader range of indicators of the quality of end-of-life care alongside the place of death. **Full text:** https://goo.gl/ooKZRE

**N.B.** Additional articles on end-of-life care for people living with Alzheimer's and other forms of dementia are noted in the 21 August 2017 issue of Media Watch (#526, p.15).

### End-of-life care in Switzerland

### Fear, pain, denial, and spiritual experiences in dying processes

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 21 August 2017 – There is a lack of deeper understanding of patients' inner processes to which care should respond. In this study, the authors hypothesized that fear/pain/denial would happen simultaneously and be associated with a transformation of perception from ego-based (pre-transition) to ego-distant perception/consciousness (post-transition) and that spiritual (transcendental) experiences would primarily occur in periods of calmness and post-transition. Parameters for observing transformation of perception (pre-transition, transition itself, and post-transition) were patients' altered awareness of time/space/body and patients' altered social connectedness. Most patients [i.e., study participants] showed at least fear and pain once. Many seemed to have spiritual experiences and to undergo a transformation of perception only partly depending on medication. Line graphs representatively illustrate associations between fear/pain/denial/spiritual experiences and a transformation of perception. No trajectory displayed uninterrupted distress. Many patients seemed to die in peace. Previous near-death or spiritual/mystical experiences may facilitate the dying process. Full text: https://goo.gl/B6aKUH

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Back Issues of Media Watch <a href="http://goo.gl/frPqZ5">http://goo.gl/frPqZ5</a>

#### End-of-life care in Scotland

## Developing design principles for a virtual hospice: Improving access to care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 23 August 2017 – Providing access to hospice services will become increasingly difficult due to the pressures of an ageing population and limited resources. To help address this challenge, a small number of services called virtual hospice have been established. This paper presents early-stage design work on a virtual hospice to improve access to services provided by a hospice (Highland Hospice) serving a largely remote and rural population in Scotland. A number of themes and barriers to accessing Highland Hospice services were identified. In response, an initial set of seven design principles was developed. Design principles are high-level guidelines that are used to improve prioritisation and decision making during the design process by ensuring alignment with research insights. The design principles were piloted with a group of stakeholders and gained positive feedback. These principles, encompassing digital and non-digital guidelines, or the design approach could be applied by other hospices in the U.K. or overseas. Abstract: <a href="https://goo.gl/FgSRYk">https://goo.gl/FgSRYk</a>

Noted in Media Watch 15 December 2014 (#388, p.12):

■ INTERNATIONAL JOURNAL OF INTEGRATED CARE | Online - 3 December 2014 - 'The virtual hospice: A working, integrated end-of-life care programme.' The virtual hospice is a working integrated end-of-life care programme, in development, for the people of Maitland, New South Wales, Australia. It was "built" in response to: 1) The inequity and inconsistency in the provision of palliative care for people dying at home, in hospital, and in aged care facilities; 2) The apparent disconnectedness experienced by individuals living, working, and dying in our local community; and, 3) The ever increasing medicalization of death and dying in Australian society. Abstract: https://goo.gl/7zX8br

**N.B.** The authors point out that there is a small number of services called "virtual hospice," among them the Canadian Virtual Hospice (CVH), a well-established, web-based platform that allows Canadians to email questions to a palliative care team. About CVH: <a href="https://goo.gl/7qTmqY">https://goo.gl/7qTmqY</a>

## A survey of Canadian nephrologists assessing prognostication in end-stage renal disease

CANADIAN JOURNAL OF KIDNEY HEALTH & DISEASE | Online – 18 August 2017 – Patients with end-stage renal disease (ESRD) frequently have a relatively poor prognosis with complex care needs that depend on prognosis. While many means of assessing prognosis are available, little is known about how Canadian nephrologists predict prognosis, whether they routinely share prognostic information with their patients, and how this information guides management. Less than half of the respondents indicated they always or often make an explicit attempt to estimate and/or discuss survival with ESRD patients not on dialysis, and 25% reported they do so always or often with patients on dialysis. Survival estimation is most frequently based on clinical gestalt. Respondents endorse a wide range of issues that may be influenced by prognosis, including advance care planning, transplant referral, choice of dialysis access, medication management, and consideration of conservative care. Full text: <a href="https://goo.gl/yRn4Qn">https://goo.gl/yRn4Qn</a>

Noted in Media Watch 17 April 2017 (#508, p.8):

CURRENT OPINION IN NEPHROLOGY & HYPERTENSION | Online – 7 April 2017 – 'Palliative and end-of-life care in nephrology: Moving from observations to interventions.' In comparison with patients who have other serious illnesses, patients with advanced kidney disease have a higher rate of intensive care utilization at the end of life and receive palliative care (PC) less frequently. Consensus and clinical practice guidelines have therefore recommended the incorporation of PC earlier in the disease trajectory. Abstract: https://goo.gl/QGfH50

**N.B.** Palliative and end-of-life care in nephrology are noted in the 24 April 2017 issue of Media Watch (#509, p.15).

# A comparison of the influence of anticipated death trajectory and personal values on end-of-life care preferences: A qualitative analysis

CLINICAL GERONTOLOGIST | Online – 16 August 2017 – Reluctance to burden close others was the most frequently voiced personal value across all conditions affecting end of life (EoL) preferences, followed by the personal value of quality of life. Concern about whether one's wishes would be honored was more commonly voiced in the context of hypothetical, prospective terminal cancer than in neurological conditions. Respondents who voiced desire for autonomy in how they would die clearly attributed extreme pain as the primary influence on EoL preferences. Because personal values do influence EoL preferences, care should be taken to ascertain patient values when presenting diagnoses, prognoses, and treatment options. **Abstract:** https://goo.gl/wbdN1X

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

## Variation in end-of-life care is an open invitation for Accountable Care Organization innovation

HEALTH AFFAIRS | Online – 25 August 2017 – End-of-life (EoL) care is ripe for transformation by accountable care organizations (ACOs), which have the right incentives to tackle the widespread variation in use, quality, and costs that now characterize health care at the end of life. Despite significant attention to ACOs from researchers and policy makers, little is known about how ACOs are approaching EoL care. While ACOs have been shown to affect the use of certain health care services, particularly in the post acute environment, discussions of the impact of ACOs on EoL care are conspicuously absent. Undoubtedly, the lack of attention to EoL care is attributable, in part, to ACOs being relatively nascent entities. However, as ACOs evolve and become more risk-bearing, they are increasingly likely to adopt strategic approaches aimed at improving the EoL experiences of beneficiaries while ensuring efficient use of health care services. The Medicare hospice benefit contributes to the extreme variation in hospice use... Full text: <a href="https://goo.gl/pNtjEd">https://goo.gl/pNtjEd</a>

# Communication in heart failure and palliative care

HEART FAILURE REVIEWS | Online - 21 August 2017 - Communicating difficult information is an essential skill for clinicians of every specialty. The clinical complexity of the heart failure disease process lends itself to important opportunities to determine patient preferences about medical decisions and share information about prognosis. Nevertheless, traditionally most communication between clinicians and patients with heart failure has focused primarily on pathophysiology and treatment options. Studies indicate that patients and families wish to engage with their cardiologists in advance care planning and, when appropriate, end-of-life decision-making. Critical to whole-person care, this review describes several important communication strategies that enhance patient and family support through the inevitable rises and falls of progressive heart failure. **Abstract:** https://goo.gl/MBfte4

#### Related

- AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online 22 August 2017 'Patterns of palliative care referral in patients admitted with heart failure requiring mechanical ventilation.' Palliative care (PC) is recommended for advanced heart failure (HF) by several major societies, though prior studies indicate it is underutilized. The use of PC for patients with advanced HF increased during the study period [2006-2012]; however, PC remains underutilized in this setting. Patient factors such as race and socio-economic status affect access to PC. Abstract: <a href="https://goo.gl/VcMEGq">https://goo.gl/VcMEGq</a>
- JOURNAL OF CARDIAC FAILURE | Online 22 August 2017 'End-of-life discussions in patients with heart failure.' The vast majority of patients hospitalized with acute decompensated heart failure [i.e., study participants] say they have never discussed their wishes for end-of-life (EoL) care with their doctor. EoL discussions were no more common in patients with worse prognosis. Patients who recall having discussions were more knowledgeable about EoL options and more likely to have completed an advance directive. Abstract: <a href="https://goo.gl/Vm1ZRH">https://goo.gl/Vm1ZRH</a>

**N.B.** Additional articles on end-of-life care for people living with heart failure are noted in the 21 August 2017 issue of Media Watch (#526, pp.11-12).

#### End-of-life care in Finland

## Advance directives and the descendant argument

HEC FORUM | Online – 16 August 2017 – By issuing an advance treatment directive, an autonomous person can formally express what kinds of treatment she wishes and does not wish to receive in case she becomes ill or injured and unable to autonomously decide about her treatment. While many jurisdictions and medical associations endorse them, advance treatment directives have also been criticized. According to an important criticism, when a person irreversibly loses her autonomy what she formerly autonomously desired ceases to be of (central) importance in deciding about her treatment. The medical ethical debate regarding different possible ways of solving the problem on which the criticism is based has grown exceedingly intricate. Instead of assessing the developments made in the debate so far, the author presents a thought experiment – built around a suicide case – which suggests that the problem is not as intractable as it has generally been deemed to be.

#### **Worth Repeating**

'Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review' (p.15), in *Palliative Medicine*.

Abstract: https://goo.gl/JR8Lvg

### Paediatric palliative care and intellectual disability: A unique context

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 23 August 2017 – Paediatric palliative care (PC) is a nuanced area of practice with additional complexities in the context of intellectual disability. There is currently minimal research to guide clinicians working in this challenging area of care. This study describes the complex care of children with life-limiting conditions and intellectual disability by means of a literature synthesis and commentary with "best-practice" guide. As few articles concerning children with intellectual disability and PC needs were identified by formal systematic review, the authors' expert consensus group has drawn from the paediatric palliative, oncology and adult intellectual disability literature to highlight common clinical challenges encountered in the day-to-day care of children with intellectual disability and life-limiting conditions. A longitudinal child- and family-centred approach is key to ensuring best-practice care for families of children with life-limiting conditions and intellectual disability. **Abstract:** https://goo.gl/sPB6vw

# Supporting end-of-life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 16 August 2017 – The United Nations' Convention on the Rights of Persons with Disabilities promotes the use of supported decision making (SDM) in lieu of substitute decision making. To date, there has been a lack of focus on SDM for people with severe or profound intellectual disability, including for end-of-life (EoL) decisions. All five case studies identified that supporters were most effective in providing decision-making support for participants when they were relationally close to the person and had knowledge of the person's life story, particularly in relation to events that demonstrated preference. Findings from this study provide new understandings of SDM for people with severe or profound intellectual disability and have particular relevance for supporting decision making at the EoL. **Abstract:** <a href="https://goo.gl/txnHyH">https://goo.gl/txnHyH</a>

Cont. next page



#### 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 beginning on p.16.

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

JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES | Online – 25 July 2016 – 'Intellectual disabilities and decision making at end of life: A literature review.' Individuals with an intellectual disability are vulnerable to having end-of-life (EoL) decisions made for them merely due to the presence of a disability. As a result, decisions made by others may not reflect the exact wishes of the individual. The findings from this review provide a foundation for a decision tree in EoL decision making for individuals with an intellectual disability. Abstract: <a href="http://goo.gl/sCALxr">http://goo.gl/sCALxr</a>

**N.B.** Selected articles on end-of-life care for people living with intellectual disabilities are noted in the 14 August 2017 issue of Media Watch (#525, p.11).

#### Integration of palliative care into standard oncology care

#### Highlighting implementation findings in early palliative care

JOURNAL OF ONCOLOGY PRACTICE | Online – 22 August 2017 – There may be some parallels between readers of Cooks Illustrated [a unique trial-and-error approach to finding and reporting the best way to prepare a specific recipe] and readers of the Walling et al and Puckett et al studies.<sup>1,2</sup> The authors of those studies are attempting to determine what constitutes the best components of



early, integrated palliative care (PC) in their own cancer centers. Discussion of integrating PC early in the course of advanced cancer occurred soon after the publication of a recommended guideline from the American Society of Clinical Oncology after they closely examined the results of several randomized and quasi-experimental trials that demonstrated improved outcomes for patients and their family caregivers. That guideline and the associated trials indicated that integrated and timely PC is worth implementing. The important implementation strategies noted by Walling *et al* and Puckett *et al* are typically not the centerpiece of reports on study results. But they represent some of the most critical lessons learned and real-world factors that influence implementation of research findings into practice. Although the past decade has seen the successful testing of a new paradigm of early PC, the tools and components for implementing it into practice are still being established. Until then, integrating early PC into clinical practice will remain a clinical trial success but not a widespread clinical reality. **Full text:** <a href="https://goo.gl/UHTwa3">https://goo.gl/UHTwa3</a>

- 'Effect and efficiency of an embedded palliative care nurse practitioner in an oncology clinic,' Journal of Oncology Practice, published online 16 August 2017. Abstract: <a href="https://goo.gl/6cV9dg">https://goo.gl/6cV9dg</a>
- 'Preventing discontinuation of radiation therapy: Predictive factors to improve patient selection for palliative treatment,' *Journal of Oncology Practice*, published online 31 July 2017. **Abstract:** <a href="https://goo.gl/V8GWYD">https://goo.gl/V8GWYD</a>
- 3. 'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,' *Journal of Clinical Oncology*, 2017;35(1):96-112. [Published online 31 October 2016; noted in the 31 October 2016 issue of Media Watch (#486, p.7)] **Full text:** <a href="https://goo.gl/RGjFMP">https://goo.gl/RGjFMP</a>

#### Related

JOURNAL OF ONCOLOGY PRACTICE | Online – 22 August 2017 – 'How can we improve the collaborative care between the primary oncologist and the palliative care specialist in caring for patients with serious illness?' Beneficence should be the goal of the oncologist and palliative care consult team to provide an honest, compassionate, and complementary patient-centered discussion and treatment options whether illness is curable, chronic, or terminal. Both specialties have a duty to collaborate, educate, and support patients, their families, and each other on all the options for care across each stage of disease. Full text: <a href="https://goo.gl/ozQGL3">https://goo.gl/ozQGL3</a>

- JOURNAL OF ONCOLOGY PRACTICE | Online 22 August 2017 'Effect of palliative care on aggressiveness of end-of-life care among patients with advanced cancer.' This population-based study found that palliative care (PC) substantially decreased health-care use among Medicare beneficiaries with advanced cancer. Given the increasing number of elderly patients with advanced cancer, this study emphasizes the importance of early integration of PC alongside standard oncologic care. Abstract: <a href="https://goo.gl/gcmuHo">https://goo.gl/gcmuHo</a>
- JOURNAL OF ONCOLOGY PRACTICE | Online 22 August 2017 'Identifying and managing undue influence from family members in end-of-life decisions for patients with advanced cancer.' The authors explain how undue influence may present itself in the clinic and distinguish it from ethically permissible expressions of relational autonomy. In addition, they lay out a process by which any clinician suspecting undue influence may gather additional information and, if necessary, conduct a family meeting to address the undue influence. Abstract: <a href="https://goo.gl/h46yoa">https://goo.gl/h46yoa</a>
- JOURNAL OF ONCOLOGY PRACTICE | Online 22 August 2017 'What enables oncologists to discuss goals of care with their patients? Practical ways toward a culture of kindness, transparency, and responsibility.' What happens when oncologists hesitate to discuss goals of care now, in 2017? The evidence showing patient benefit from these discussions is clear, and the communication skills are defined, but the context has changed. Many oncologists now have some access to palliative care specialists. The unintended consequence of this change is that it is now possible for them to outsource the goals of care conversation. Full text: https://goo.gl/U6MsrT

Noted in Media Watch 21 August 2017 (#526, p.13):

■ JOURNAL OF ONCOLOGY PRACTICE | Online — 16 August 2017 — 'Palliative care in special settings of cancer care.' Tribalism is a bold word that summarizes the behaviour of people who identify themselves as part of a group. Oncology as a whole is a tribe with its own customs, language, and conventions. Within oncology, surgical, radiation, medical, gynecologic, malignant hematologic, transplantation, and pediatric fields are distinct tribes with distinctive rites and rituals of usual behavior that are carried out in special settings. Successful integration of palliative care requires a keen and unabashed recognition of this. Full text: https://goo.gl/aCjcfc

#### Development and validation of a family meeting assessment tool

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 August 2017 – There is limited evidence on how to assess best practice behaviors during end of life family meetings. Building on evidence from published studies and accrediting agency guidelines, an expert panel ... developed the Family Meeting Assessment Tool (FMAT). All fourth-year medical students and eight geriatric and palliative medicine fellows were invited to participate in a Family Meeting Objective Structured Clinical Exam, where each trainee assumed the physician role leading a complex family meeting. Two evaluators observed and rated randomly chosen students' performances using the FMAT during the exam. Expert-based content, high inter-rater reliability, good internal consistency and ability to predict educational level provided initial evidence for construct validity for this novel assessment tool. **Abstract:** <a href="https://goo.gl/SQ9cw6">https://goo.gl/SQ9cw6</a>

**N.B.** Additional articles on family conferences/meetings in the context of palliative and end-of-life care are noted in the 14 November 2017 issue of Media Watch (#487, p.10); selected articles on the related role of surrogate decision makers are noted in the 24 July 2017 issue of the weekly report (#522, p.11).

#### End-of-life care in Australia

## The role of palliative care psychiatry in the treatment of life-threatening illnesses

MENTAL HEALTH MATTERS, 2017;4(4):50-52. The reality of being alive is that it is a transient state. One that is finite and that will ultimately end. This reality is however, one that we avoid discussing and perhaps, even acknowledging. Because we are so reluctant to talk about death, we are also very unlikely to plan for it, or to express our treatment wishes to our loved ones in the event that we become unwell. A survey in Australia revealed that 82% of Australians think that talking to your family about your end of life wishes is important. Yet only 27 % have ever done so. **Abstract:** https://goo.gl/gHsNhy

Noted in Media Watch 1 August 2016 (#473, p.11):

■ BMC PSYCHIATRY | Online – 22 July 2016 – 'Palliative psychiatry for severe persistent mental illness as a new approach to psychiatry? Definition, scope, benefits, and risks.' Despite psychiatrists' efforts to prevent mental illness and to promote recovery, some patients will develop "severe persistent mental illness." These represent a particularly vulnerable population, at risk of either therapeutic neglect or overly aggressive care. Abstract: <a href="http://goo.gl/M1GRkY">http://goo.gl/M1GRkY</a>

## Healthcare professionals' views on palliative care for inpatients in Tanzania: A qualitative study

PALLIATIVE & SUPPORTIVE CARE | Online – 22 August 2017 – Thirty-two healthcare workers were interviewed via 7 focus group discussions and one semi-structured interview. Four major themes were identified. First, participants held strong views on what factors were important to enable individuals with a life-limiting diagnosis to live and die well. Arriving at a state of "acceptance" was the ultimate goal; however, they acknowledged that they often fell short of achieving this for inpatients. Thus, the second theme involved identifying the "barriers" to delivering palliative care (PC) in hospital. Another important factor identified was difficulty with complex communications, particularly "breaking bad news," the third theme. Fourth, participants were divided about their personal preferences for "place of end-of-life care (EoLC)," but all emphasized the benefits of the hospital setting so as to enable better symptom control. Despite the fact that all the healthcare workers interviewed were regularly involved in providing palliative and EoLC, they had received limited formal training in its provision, although they identified such training as a universal requirement. Abstract: <a href="https://goo.gl/2hqWGE">https://goo.gl/2hqWGE</a>

## End-of-life and bereavement care in pediatric intensive care units

PEDIATRIC CLINICS OF NORTH AMERICA | Online - 18 August 2017 - Overall, pediatric mortality is decreasing in the U.S. In 1980, more than 64,000 infants and children less than 15 years of age died in the U.S. In striking contrast, 2014 data show that number has almost decreased in half with only 32,295 reported deaths among this age group. Similarly, mortality rates among pediatric intensive care unit (PICU) admissions have also decreased over time. Three recent multicenter studies have reported PICU mortality rates less than 3%. Most childhood deaths in the U.S. occur in hospitals and most of these in intensive care settings. Thus, the ability to provide high-quality end-of-life (EoL) care is an essential component of successful pediatric critical care programs. The ability to anticipate. identify, and treat pain and suffering at EoL, while concurrently attending to the psychosocial

needs of dying children and their families, may facilitate a peaceful death and help families adjust during bereavement. Parents often experience reduced mental and physical health following the loss of their child. EoL care in the pediatric intensive care unit is often associated with challenging ethical issues. Clinicians must maintain a sound and working understanding of these matters. **Abstract:** https://goo.gl/iLf7pb

#### Spiritual care of children and their families

JOURNAL PEDIATRIC PALLIATIVE & HOSPICE CARE | Online – Accessed 23 August 2017 – The current issue of the journal offers a collection of articles that explore issues related to spiritual care of children and their families. https://goo.gl/xHaQzP

Noted in Media Watch 5 June 2017 (#515, p.16):

■ PEDIATRIC CRITICAL CARE MEDICINE | Online – 29 May 2017 – 'Disenfranchised grief in the PICU: Crying for attention.' The death of any child is distressing to parents, family, friends, and healthcare staff alike. However, the close family circle is accorded the right to grieve by society, as the nature of the relationship with the child is acknowledged and socially validated. The relationship between the child and the staff caring for the child is not acknowledged to the same extent, and this may cause difficulties for staff who grieve following the death of the child. This experience is repeated many times when working in the PICU. Abstract: <a href="https://goo.gl/quMdRz">https://goo.gl/quMdRz</a>

**N.B.** Additional articles on end-of-life care in the pediatric intensive care unit are noted in the 11 July 2016 issue of Media Watch (#470, p.8).

## Why doctors should draw genograms - including their own

POSTGRADUATE MEDICAL JOURNAL, 2017;93(1103:575-756. Virtually every doctor will have learnt at medical school how to draw a genogram. Genograms ... are basically family trees, but annotated with further relevant information according to the clinical context. In some specialties like clinical genetics or haematology, they are used routinely to record which members of a patient's family carry a particular gene or suffer from an expressed inherited disorder. In specialties like family medicine, paediatrics, palliative care or psychiatry, they are usually taken in order to gain a more informed understanding of a patient's personal circumstances and the background to their presentations. Indeed, some practitioners in these fields regard genograms as an indispensable tool for understanding family systems and dynamics, or even for just remembering details like everyone's names and ages. Full text: https://goo.gl/uoMbgY

Noted in Media Watch 21 May 2016 (#454, p.8):

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(2):66-69. 'Are genograms useful holistic
assessment tools in palliative care? A literature review.' Genograms are increasingly used in palliative care to assess the emotional and practical support needs of patients and families. On the whole,
the literature considers genograms favourably, but it does not provide much hard evidence to support
their use.

N.B. Access to the European Journal of Palliative Care requires a subscription: http://goo.gl/WKvCC4

# Palliative care consultants' ethical concerns with advanced cancer patients participating in phase 1 clinical trials: A case study

PROGRESS IN PALLIATIVE CARE | Online – 21 August 2017 – Patients with advanced cancer often continue to choose aggressive interventions and/or treatments up until the final stages of life. This clinical approach may compromise the preservation of a patient's quality of life, and secondarily, contributes to higher healthcare costs. Therefore, the ethics of enrolling terminal cancer patients in clinical trials which are testing new, aggressive chemotherapy agents requires careful discussion between the oncology and the palliative care (PC) team. The authors present the case of a patient with stomach cancer admitted to a clinical trial at a very advanced stage of her disease. A number of clinical and ethical difficulties encountered by the PC team are discussed as well as possible solutions. **Abstract:** https://goo.gl/9hRUxa

## End-of-life care in Australia

## A practice model for rural district nursing success in end-of-life advocacy care

SCANDANAVIAN JOURNAL OF CARING SCIENCES | Online – 24 August 2017 – A model developed by gathering and comparing district nursing experiences and understanding using mixed methods and existing theory offers evidence for practice of a philosophy of successful person-centred advocacy care in a field of nursing that lacks specific guidance. The model illustrates rural district nurse advocacy success based on respect for the rights and values of people. Advocacy action is motivated by the emotional responses of nurses to the end-of-life (EoL) vulnerability people experience. The combination of willing investment in relationships, knowing the rural people and resources, and feeling supported, together enables district nurses to develop therapeutic emotional intelligence. This skill promotes moral agency in reflection and advocacy action to overcome emotional and ethical care challenges of access and choice using holistic assessment, communication, organisation of resources and empowering support for the self-determination of person-centred EoL goals. **Abstract:** <a href="https://goo.gl/tSR7P2">https://goo.gl/tSR7P2</a>

# **Palliative Care Network Community**

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

#### Assisted (or facilitated) death

Representative sample of recent journal articles:

- BIOETHICS | Online 23 August 2017 'Two kinds of physician-assisted death.' The author argues that the concept "physician-assisted suicide" covers two procedures that should be distinguished: giving someone access to humane means to end his own life, and taking co-responsibility for the safe and effective execution of that plan. He argues that we should expect the laws that permit these two kinds of "assistance" to be different in their justificatory structure. Abstract: <a href="https://goo.gl/ScLYgH">https://goo.gl/ScLYgH</a>
- CANADIAN JOURNAL OF NEUROLOGICAL SCIENCES | Online 14 August 2017 'Medical assistance in dying and the neurosurgeon: Position statement of the Canadian Neurosurgical Society.' This position statement was generated by the Society's sub-committee on Medical Assistance in Dying (MAiD). The contents of the position statement were informed by a Society members' survey on MAiD as well as a forum on the issue that took place last year. Abstract: https://goo.gl/c9JNCY
- FAMILY COURT REVIEW, 2017;55(3):430-443. 'Extending the practice of physician-assisted suicide to competent minors.' As the practice of physician-assisted suicide becomes accepted among states [in the U.S.], competent minors continue to be excluded from legislative and judicial decisions. Regardless of parental consent, states institute an age requirement of eighteen years old for participants of physician-assisted suicide. This note proposes that states amend their physician-assisted suicide statutes to 1) Remove any age restriction; 2) Create a standard of competency that minors must meet to be eligible for physician-assisted suicide; and, 3) Implement a procedure to determine whether a minor meets the competency standard. Abstract: <a href="https://goo.gl/cZS6pX">https://goo.gl/cZS6pX</a>

## **Worth Repeating**

Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review

PALLIATIVE MEDICINE, 2016;30(9):807-824. Administration of non-beneficial life-sustaining treatments in terminal elderly patients still occurs due to lack of knowledge of patient's wishes or delayed physician-family communications on preference. Twenty-four eligible articles from 10 countries including 23,914 subjects met the inclusion criteria, mostly using qualitative or mixed methods, with the exception of two cohort studies. The influence of advance care documentation (ACD) on initiation of end-of-life (EoL) discussions was predominantly based on perceptions, attitudes, beliefs and personal experience rather than on standard replicable measures of effectiveness in triggering the discussion. While health professionals reported positive perceptions of the use of ACD (18/24 studies), actual evidence of their engagement in EoL discussions or confidence gained from accessing previously formulated wishes in ACD was not generally available. Perceived effectiveness of ACD in encouraging EoL discussions appears to be high but is mostly derived from low-level evidence studies. This may indicate a willingness

and openness of patients, surrogates and staff to perceive advance directives as an instrument to improve communication, rather than actual evidence of timeliness or effectiveness from suitably designed studies. The assumption ACD will lead to higher physicians' confidence or engagement in communicating with patients-families could not be objectively demonstrated in this review. [First published online 7 March 2016; noted in Media Watch 14 March 2016 (#453, p.14)] Abstract: http://goo.gl/1JDdAH

## Palliative Medicine



The authors of this article were the recipients of the prestigious *Palliative Medicine* Paper of the Year Award, which was presented at the 15th World Congress of the European Association for Palliative Care (EAPC) held in Madrid, Spain, in May 2017. See EAPC blog for a discussion of the study and for a link to the **full text**: <a href="https://goo.gl/PbC1UF">https://goo.gl/PbC1UF</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.

#### **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.

#### Media Watch: Online

## International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/nZMuK7

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 '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: <a href="https://goo.gl/BLgxy2">https://goo.gl/BLgxy2</a> [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: <a href="http://goo.gl/o7kN3W">http://goo.gl/o7kN3W</a> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

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

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





# 14 October 2017

Universal health coverage and palliative care - Don't leave those suffering behind

https://goo.gl/diYn7i

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