

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

Expanding age-specific transition services: Scroll down to [Specialist Publications](#) and 'Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services' (p.13), in *Journal of Advance Nursing*.

Canada

Mobile palliative care team dignifies Calgary's dying homeless: "They deserve it."

ALBERTA | Global TV News (Calgary) – 24 July 2018 – As often as they can, the doctor and nurse duo travel every corner of Calgary in search of their terminally ill patients. All are transient. Some are couch surfing, some live in their car or under a bridge, others in a shelter. The Calgary allied mobile palliative program (CAMPP) compassionately gives end-of-life care to the homeless. Rachael Edwards is the registered nurse for the CAMPP team. She knows these vulnerable patients can't go regularly to clinics or hospitals, which is why CAMPP meets them exactly where they are, wherever that may be. "We have folks in suburbs and harm-reduction buildings and folks that live down the river. We have to be creative and figure out how to do this because they deserve it," Edwards said. The team was created less than two years ago and is privately funded. CAMPP has cared for over 30 patients so far with a current caseload of 18. Many of the people CAMPP cares for say they have faced judgements in the medical system and have lost faith in main-

stream care. The CAMPP team knows it can't save them from their medical fate, but it can make a difference in their final days or months. <https://goo.gl/19HVHr>

European Journal of

Palliative Care



A JOURNAL OF THE EUROPEAN ASSOCIATION FOR PALLIATIVE CARE

The homeless: a vulnerable population with poor access to palliative care

■ In his regular column, **Barry Ashpole** presents a selection of abstracts that highlight new findings and trends in the diverse and rapidly expanding body of research in the field of palliative and end-of-life care.

See March/April issue of the *European Journal of Palliative Care* (p.89). Access requires a subscription. **Contents page:** <https://goo.gl/7w8HS9>

N.B. Additional articles on palliative and end-of-life care initiatives for the homeless in Canada noted in the 26 February 2018 issue of Media Watch (#552, p.2). CAMPP website: <https://goo.gl/VuHVEz>

U.S.A.

Hospitals reflexively put patients who may be dying on breathing machines. It's time to rethink that

TIME MAGAZINE | Online – 26 July 2018 – Breathing machines were originally designed to reduce the work of breathing until surgery, an infection or some other acute critical condition was resolved. But they are now commonly used for seriously ill older adults. If they are lucky enough to survive, they often require prolonged time in hospitals and then, for days to weeks if not months, a rehabilitation facility. In 2011, 497,496 older adults received this care in the U.S. – an amount projected to double by 2020. The rate of increase is four-fold higher in patients with dementia whose conditions may never end. Part of the reason for the popularity of this undesirable process is that, when faced with a life-or-death decision, selecting the appropriate seriously ill patients who recover from the breathing machine is not straightforward. Predicting how much longer the patient will live, managing the acute illness, exploring the values and preferences of the patient and making a recommendation on how to proceed – these actions are complex, especially during a life-or-death situation. It is in these moments that doctors must choose when intervention itself is the best approach to help the patient, particularly if they are unlikely to recover. Regarding predicting how much longer patients will live, I recently published a study about what would happen to older adults if they were placed on a breathing machine.¹ I analyzed 35,000 patients who were older than 65 years and placed on breathing machines, across 262 hospitals between 2008

and 2015. A third of those patients died in the hospital. Most survivors (63%) were discharged to locations other than their home, presumably to nursing facilities... <https://goo.gl/yPU5Fp>

Specialist Publications

'Development of hospice and palliative medicine knowledge and skills for emergency medicine residents: Using the Accreditation Council for Graduate Medical Education Milestone Framework' (p.6), in *Academic Emergency Medicine: Education & Training*.

'Getting to the heart of the matter: A regional survey of current hospice practices caring for patients with heart failure receiving advanced therapies' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'The evolution of palliative care within the American Indian Health System' (p.9), in *Cancer Health Disparities*.

'End of life, withdrawal, and palliative care utilization among patients receiving maintenance hemodialysis therapy' (p.10), in *Clinical Journal of the American Society of Nephrology*.

'Effects of caregiver and decedent characteristics on Consumer Assessment of Healthcare Providers & Systems Hospice (CAHPS) Survey scores' (p.15), in *Journal of Pain & Symptom Management*.

1. 'Prognosis after emergency department intubation to inform shared decision-making,' *Journal of the American Geriatrics Society*, published online 15 March 2018. **Abstract:** <https://goo.gl/z1uEgJ>



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>

The mystery of end-of-life rallies

THE NEW YORK TIMES | Online – 24 July 2018 – Palliative care (PC) experts say it is not uncommon for people in hospice care to perk up briefly before they die, sometimes speaking clearly or asking for food. Anecdotally, doctors and nurses interviewed for this article said that a striking number of their dying patients had experienced a rally, also known as terminal lucidity. Bounce-backs generally last only a couple hours, but some go on for so long that the patients can take a break from a hospice for a few months. Dr. Craig Blinderman, the director of adult palliative medicine at the Columbia University Medical Center, hears lots of accounts. Yet evidence-based data is elusive, if nonexistent, he said. Aside from the challenges of catching dying people at the moment of springing back, it'd be tough to get the medical ethics board to determine that the research would benefit the

patient. This type of study would require constant drawing of blood and monitoring of patients, which runs counter to the quiet fade away that is a signature element of PC. These windows of energy can startle family members sitting at the bedside. Those who hold out hope that their loved ones may somehow recover may see the comebacks as encouraging. Some find the little flickers disturbing or even heartbreaking. <https://goo.gl/W2MLDz>

[Specialist Publications](#)

'The impact of unusual end-of-life phenomena on hospice palliative care volunteers and their perceived needs for training to respond to them' (p.16), in *Omega – Journal of Death & Dying*.

Noted in Media Watch 17 July 2017 (#521, p.4):

- *THE NEW YORK TIMES* | Online – 11 July 2017 – **'The gentler symptoms of dying.'** While some of the symptoms of dying, like the death rattle, air hunger and terminal agitation, can cause alarm in witnesses, other symptoms are more gentle. The human body's most compassionate gift is the interdependence of its parts. As organs in the torso fail, the brain likewise shuts down. Failing lungs decrease oxygen and increase carbon dioxide in the blood, both of which slow cognitive function. The mysterious exception is "terminal lucidity," a term coined by the biologist Michael Nahm in 2009 to describe the brief state of clarity and energy that sometimes precedes death. <https://goo.gl/Szo5Vf>

From the archives:

- *ARCHIVES OF GERONTOLOGY & GERIATRICS*, 2012;55(1):138-142. **'Terminal lucidity: A review and a case collection.'** The authors review a range of terminal lucidity cases in order to encourage investigation of the mechanisms involved and possible insights into both the neuroscience of memory and cognition at the end of life and treatment of terminal illness. Several of these accounts suggest that during terminal lucidity, memory and cognitive abilities may function by neurologic processes different from those of the normal brain. Significant contributions to better understanding the processes involved in memory and cognition processing might be gained through in-depth studies of terminal lucidity. **Abstract:** <https://goo.gl/ny2Qwt>

House passes bipartisan hospice bill strengthening physician training, patient outreach

WASHINGTON DC | *Home Health Care News* (Chicago, Illinois) – 23 July 2018 – The U.S. House of Representatives passed the Palliative Care & Hospice Education Training Act (PCHETA), a bipartisan piece of legislation designed to expand and strengthen end-of-life care through outreach and training programs. PCHETA was passed by a voice vote. Voice votes are typically reserved for issues expected to pass or fail by a landslide. PCHETA authorizes the U.S. Department of Health & Human Services to award grants or contracts for palliative care (PC) and hospice education centers. It also promotes career development of physicians and nurses in PC, while encouraging research and outreach efforts. Multiple lawmakers expressed their support for the hospice bill prior to the vote, specifically citing hospice and PC's ability to boost patients' quality of life and decrease overall health care costs as benefits. PCHETA, originally introduced in March of last year, received unanimous support in the House Energy & Commerce Committee and the health subcommittee. <https://goo.gl/BRcDTs>

Hospice looks at adding “death doulas” for end-of-life care

FLORIDA | *The Florida Times-Union* (Jacksonville) – 22 July 2018 – “Hope just walked in the room,” is how Nada Frazier greets each patient whether at home, a hospice, a nursing facility or hospital. Bringing comfort, standing vigil and facilitating preparations during life’s most difficult time, there is no more needed feeling than hope while preparing for death. Frazier, whose first name means “hope” in Slavic, has provided just that since she was a young girl living on her grandma’s farm, witnessing animal life cycles and helping the elderly family members find peace in their final months. Whether serving as a certified end-of-life (EoL) doula, a clinical pastoral education chaplain intern or hospice volunteer, her experience helping people deal with and talk about death has resulted in her being a part of a new chapter for the National Hospice & Palliative Care Organization as it explores incorporating EoL doulas into its many roles.¹ “Doula,” from the Greek word for a female servant, is used by people who provide support and comfort to people during pregnancy and – more recently – to those who are dying. The national hospice organization announced last month the formation of a council to review doula collaboration with hospice services and explore how it could be added to its care program, whether through agency staff, trained volunteers, or as independent contractors. <https://goo.gl/8Vtc5F>

1. ‘End-of-life doula council announced,’ National Hospice & Palliative Care Organization, June 2018. <https://goo.gl/iH1bgk>

Noted in Media Watch 28 May 2018 (#565, p.8):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2018;25(7):64-67. ‘**End-of-life doulas: What we can offer at the most difficult time of life.**’ Birth doulas provide support and guidance to mothers and mothers-to-be at the start of life; end-of-life doulas provide practical and emotional support for people who are dying and the loved ones they will ultimately leave behind. “Doula-ing” is about the quality of the relationship with the person you’re working with; it’s about making them feel safe, comfortable and perhaps most importantly, heard. If “doula-ing,” as a verb, ever makes it into the dictionary, it will be defined as the act of listening – really listening. It’s about not feeling alone. person-centred, tailored to the individual, altering and evolving to accommodate ever-changing needs.

N.B. Additional articles on death doulas noted in this issue of Media Watch. For access options to articles published in the *European Journal of Palliative Care*: <https://goo.gl/nNQJ65>

International

New guidelines in caring for vulnerable babies launched by Lien Centre for Palliative Care

SINGAPORE | *The Straits Times* – 28 July 2018 – Parents may feel that the worst thing that could happen to them is to lose their child. Some, however, may have gone through an even more traumatic experience – on top of losing a child, they feel the medical care received by their child was inadequate or resulted in needless suffering. That is one of the reasons why the centre’s clinicians, together with those from HCA Hospice Care, KK Women’s and Children’s Hospital, National University Hospital and Singapore General Hospital, have developed Singapore’s first set of guidelines to address the complex needs of vulnerable or dying babies.¹ Other countries have come up with similar guidance documents since the 1990s, but may not have a set of formalised guidelines. Britain developed a similar set of comprehensive guidelines in 2014.² The [Lien Centre] document is organised into two sections. The first describes the needs of vulnerable babies and the scope of supportive and comfort care, such as ensuring their physical comfort. The next section is to arm healthcare professionals who manage vulnerable babies with the expertise to render the care needed, such as how to handle critical decision-making and plan for end-of-life care. There is also information on pain management and bereavement support. <https://goo.gl/hLSRT8>

1. ‘Guidance on Supportive & Comfort Care in Vulnerable Babies, 2018,’ Lien Centre for Palliative Care, July 2018. **Download/view at:** <https://goo.gl/NzHYLU>
2. ‘Practical Guidance for the Management of Palliative Care on Neonatal Units,’ Royal College of Paediatrics & Child Health, February 2014. **Download/view at:** <https://goo.gl/KVpGmg>

The incapacity crisis – a nation unprepared

U.K. | *Family Law* – 26 July 2018 – There has been growing concern in the legal profession, and amongst some of Solicitors for the Elderly's partnership organisations, that people are not planning ahead or indeed having necessary conversations with their loved ones. These conversations include wishes, beliefs, values and feelings with regard to end-of-life (EoL) care and medical treatments, as well as how they would want to be treated in specific situations where they were unable to express their views due to an accident, medical emergency or to cognitive impairment. In response to these concerns, Solicitors for the Elderly and the Centre for Future Studies produced a report warning that millions of people are leaving important EoL decisions in the hands of strangers.¹ The study found that the ever-increasing number of people living with dementia, combined with the failure to plan, exposes a looming incapacity crisis. The research revealed 97% of people have not made necessary provisions, should they lose capacity from conditions like dementia. A further 36% admit to having made no provisions at all for later life, including a will, pension, funeral plan or lasting power of attorney (LPA). A staggering 63% of people incorrectly believe that their next of kin can specify what they would have wanted if they are no longer able to, and 70% of the public would like a family member to make medical and care decisions on their behalf. This is not the

case in reality. These decisions are out of a loved ones' hands if a registered health and welfare LPA is not in place. <https://goo.gl/drQDCY>

Specialist Publications

'Assessing concordance between patient preferences in advance care plans and in-hospital care' (p.8), in *Australian Health Review*.

'Patient and caregiver involvement in formulation of guideline questions: Findings from the European Academy of Neurology Guideline on Palliative Care of People with Severe Multiple Sclerosis' (p.11), in *European Journal of Neurology*.

'Origins and effects of the 2014-2016 National Strategy for Palliative Care in Croatia' (p.12), in *Health Policy*.

'The Belgian euthanasia law and its impact on the practises of Belgian paediatric palliative care teams' (p.17), in *International Journal of Palliative Nursing*.

'From sin to treatment: A very brief survey of the relationship between political power and end-of-life decisions in Western societies' (p.17), in *Via Panoramica: Revista de Estudos Anglo-Americanos*.

1. 'The incapacity crisis – a nation unprepared. Make sure your wishes are heard,' Solicitors for the Elderly, May 2018. **Download/view at:** <https://goo.gl/atUkeD>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- FALKLAND ISLANDS | *The Daily Mirror* (London, England) – 26 July 2018 – '**Falkland Islands become first overseas British territory to vote in support of assisted dying.**' Politicians passed a motion that terminally ill residents should have the right to end their life, subject to proper safeguards. The islands' Legislative Assembly also voted to consider changing laws if the U.K. first did the same. Both motions passed by a majority of four votes to three, with one abstention. Although laws are not changing on the South Atlantic islands, campaigners hope the show of support will lead the way for other areas. <https://goo.gl/uuUY94>



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.18.

Specialist Publications

Development of hospice and palliative medicine knowledge and skills for emergency medicine residents: Using the Accreditation Council for Graduate Medical Education Milestone Framework

ACADEMIC EMERGENCY MEDICINE: EDUCATION & TRAINING, 2018;2(2):130-145. Emergency medicine (EM) physicians commonly care for patients with serious life-limiting illness. Hospice and palliative medicine (HPM) is a subspecialty pathway of EM. Although a subspecialty level of practice requires additional training, primary-level skills of HPM such as effective communication and symptom management are part of routine clinical care and expected of EM residents. However, unlike EM residency curricula in disciplines like trauma and ultrasound, there is no nationally defined HPM curriculum for EM resident training. An expert consensus group was convened with the aim of defining content areas and competencies for HPM primary-level practice in the ED setting. The American College of Emergency Physicians (Palliative Medicine Section) assembled a committee that included academic EM faculty, community EM physicians, EM residents, and nurses, all with interest and expertise in curricular design and palliative medicine. The committee peer reviewed and assessed HPM content for validity and importance to EM residency training. A topic list was developed with three domains: provider skill set, clinical recognition of HPM needs, and logistic understanding related to HPM in the ED. The group developed milestones in HPM-EM to identify relevant knowledge, skills, and behaviors using the framework modeled after the Accreditation Council for Graduate Medical Education EM milestones. **Full text:** <https://goo.gl/uaa6Ym>



Noted in Media Watch 4 June 2018 (#566, p.9):

- *INTERNATIONAL JOURNAL OF NURSING STUDIES* | Online – 23 May 2018 – ‘**Exploring the quality of the dying and death experience in the emergency department: An integrative literature review.**’ Sixteen articles are included. Eight themes emerged: 1) Care in the emergency department (ED) is about living not dying; 2) Staff perceive that death is a failure; 3) Staff feel underprepared to care for the dying patient and family in this environment; 4) There is limited time for safe standards of care; 5) Staff stress and distress; 6) Staff use of distancing behaviours; 7) The care of the dying role is devolved from medics to nurses at the end of life; and, 8) Patients and staff perceive that the ED is not the preferred place of death. **Abstract (w. link to references):** <https://goo.gl/5dwLLz>

Related

- *EMERGENCY MEDICINE JOURNAL* | Online – 24 July 2018 – ‘**Heart failure and palliative care in the emergency department.**’ The authors conducted a health records review of 500 patients with heart failure who presented to two Canadian academic hospital emergency departments (Eds) from January to August 2013. They found that few patients with heart failure had palliative care (PC) services. Additionally, the majority of those who have PC involvement do not meet current recommendations for early PC involvement in heart failure. This study suggests that the ED may be an appropriate setting to identify and refer high-risk patients with heart failure who could benefit from earlier PC involvement. **Abstract:** <https://goo.gl/N7fcyv>

N.B. Additional articles on palliative care in emergency medicine noted in the 23 April 2018 issue of Media Watch (#560, p.10).

Expressive writing. A tool to help health workers of palliative care

ACTA BIO MEDICA, 2018;89(6-S):35-42. Expressive writing is an important strategy for preventing and managing the effects of compassion fatigue. It helps educate caregivers in recognising these feelings and providing them with a “space” and a time for their reflection. This, in turn, results in significant positive repercussions on the quality of service, reducing burnout risk, implementing coping strategies, and increasing perceived work satisfaction. Reflecting occasionally in writing about ambiguous and emotionally charged situations helps in many ways: it facilitates clarification and problem-solving, and makes one more spontaneous and present in social situations, more in tune with others and available to interact. People begin to interact differently with others and see themselves in a new light after writing about an emotional subject. **Abstract:** <https://goo.gl/MQQM1E>

Getting to the heart of the matter: A regional survey of current hospice practices caring for patients with heart failure receiving advanced therapies

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 23 July 2018 – No guidelines exist regarding care for patients with advanced heart failure (HF) receiving hospice care while continuing advanced HF therapies such as left ventricular assist devices (LVADs) or continuous inotropes. Hospice specialists reported widely varied practice experiences caring for patients with HF receiving advanced therapies, noted specific challenges for care of these patients, and expressed a desire for targeted HF education. Forty-six respondents representing 23 hospices completed the survey. Over half held leadership administrative roles, and most had more than 5 years of hospice experience. Although lack of experience and cost were cited as primary barriers to providing inotrope therapy in home hospice, about half of respondents said they would manage inotropes. All participants said their respective hospices accept patients with implantable cardioverter-defibrillators; over half said they accept patients with LVADs into hospice care. Lack of experience with LVADs was the most frequently cited barrier. Most participants were interested in training and support by an advanced HF program to facilitate hospice care of patients receiving these advanced therapies. General access to hospice services for patients with HF at their organization was considered adequate by 30 of 46 participants. Most reported that referrals are made too late. **Abstract:** <https://goo.gl/UHjNdF>

N.B. Scroll back to ‘Heart failure and palliative care in the emergency department’ (p.6), in *Emergency Medicine Journal*.

Noted in Media Watch 2 July 2018 (#570, p.8):

- *EUROPEAN JOURNAL OF HEART FAILURE* | Online – 28 June 2-18 – ‘**Which patients with heart failure should receive specialist palliative care?**’ The authors investigated which patients with heart failure (HF) should receive specialist palliative care (SPC) by first creating a definition of need for SPC in patients hospitalised with HF using patient-reported outcome measures (PROMs) and then testing this definition using the outcome of days alive and out of hospital. They also evaluated which baseline variables predicted need for SPC and whether those with this need received SPC. SPC need was defined as persistently severe impairment of any PROMS without improvement (or severe impairment immediately preceding death). **Abstract:** <https://goo.gl/zn1WrH>

Noted in Media Watch 11 June 2018 (#567, p.11):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 1 June 2018 – ‘**Exploring the challenges that family caregivers faced when caring for hospice patients with heart failure.**’ Although patients with heart disease comprise the second largest diagnostic group in hospice care, the challenges faced by family caregivers (FCGs) of hospice patients with heart failure are poorly understood and often go unaddressed. This study explored the challenges and needs of FCGs of adults with advanced heart failure receiving hospice care in the home. The results provide insight to hospice social workers and researchers to develop practical tools that can be used in routine care to evaluate FCGs’ needs... **Abstract:** <https://goo.gl/cEUuxH>

Assessing concordance between patient preferences in advance care plans and in-hospital care

AUSTRALIAN HEALTH REVIEW | Online – 23 July 2018 – This retrospective study of 198 patients completing an advance care planning (ACP), of whom almost half died within the following 12 months, showed that more than 75% received hospital care fully concordant with their stated preferences and, for decedents, most died at their preferred place of death. Relatively few patients changed their documented preferences over time, and all changes were for less use of cardiopulmonary resuscitation (CPR). Instances of discordant care mostly related to the administration of supportive treatments or surgical procedures and most were justified on the basis of patient request or appropriate clinical indications. Among 108 survivors, the number of emergency department presentations and hospital admissions per patient at 12 months after ACP completion was half those seen in the 12 months before ACP completion, whereas hospital days per patient decreased by 25%. Encouraging patients with progressive chronic disease to complete an ACP reduces their risk of receiving care they do not want, reflected in decreased use of hospital care. Preferences stated in ACPs are mostly stable over time and, if changed, tend to become more conservative in terms of CPR. Conversely, preferences stated in the ACP do not, as circumstances change, bind patients or clinicians to withholding care that relieves symptoms or prevents major morbidity in the short term. **Full text:** <https://goo.gl/qNicuX>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 July 2018 – ‘**General practice palliative care: patient and carer expectations, advance care plans and place of death: A systematic review.**’ Advance care planning and the involvement of GPs were important factors, which contributed to patients being cared for and dying in their preferred place. There was no reference to general practice nurses in any paper identified. Patients and carers prefer a holistic approach to care. Proactive identification of people approaching end of life (EoL) is likely to improve all aspects of care, including planning and communicating about EoL. **Abstract:** <https://goo.gl/kRSxTS>

Supporting parents and children prior to parental death in a National Health Service setting

BEREAVEMENT CARE, 2018;37(2):67-73. The Children & Families Service in Fife Specialist Palliative Care adopts a psycho-educational model of support which offers advice and information to enable parents to prepare themselves and their children for parental dying, death and bereavement. The role of the Children & Families Practitioner is to support the family as early as possible, through each stage of their journey through bereavement, as far as possible. Working closely with school staff and other services ensures that everyone concerned has the information they need from us to support the children and young people concerned. **Abstract:** <https://goo.gl/GMdrqP>

Tracey judgement and hospice do not attempt cardiopulmonary resuscitation orders: Steady as she goes or seismic change?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 25 July 2018 – The 2014 Court of Appeals decision with respect to *Tracey vs Cambridge University Hospital* (i.e., “the Tracey judgement”) changed the requirements for discussing do not attempt cardiopulmonary resuscitation (DNACPR) decisions with patients. This study is a retrospective case note review aiming to identify any changes in practice around discussing DNACPR decisions in hospices following the judgement. Discussions with patients around DNACPR decisions increased from 31% to 60% and with relatives from 29% to 59% following the Tracey judgement. Prior to the judgement the most frequently documented reason for not discussing was to avoid distress (23%), whereas after judgement it was patients lacking capacity to engage in such a discussion (40%). There was a lack of consistency and clarity in defining the concept of “physical or psychological harm.” Future research must examine whether the judgement is delaying or preventing DNACPR decisions being made. **Abstract:** <https://goo.gl/xf9xWq>

Cont.

Noted in Media Watch 2 March 2015 (#399, p.10):

- *MEDICAL LAW REVIEW* | Online – 25 February 2015 – ‘**Tracey and respect for autonomy: Will the promise be delivered?**’ The central issue of the Court of Appeal decision in *R (Tracey) v Cambridge University Hospitals NHS Foundation Trust & Ors* concerned whether competent adults should be involved in the decision-making process for do not attempt cardio-pulmonary resuscitation (DNACPR) decisions. The Court held that patient involvement in DNACPR decisions should be the presumption, even if clinicians sincerely believed that resuscitation would be futile, unless that involvement would cause actual psychological or physical harm. This case commentary explores the potential implications of this decision. **Abstract:** <https://goo.gl/gqcjcx>

The evolution of palliative care within the American Indian Health System

CANCER HEALTH DISPARITIES | Online – 21 July 2018 – Palliative care (PC) is now considered an important quality component within cancer care and essential to the continuum of cancer care programs nationwide. American Indian and Alaska Native patients have significant differences in mortality from various cancers, and therefore PC is very important while working in parallel towards improved survival overall. In fact, PC has in some circumstances even contributed to improved survival. This article recounts the efforts made over many years to institute quality PC programs that are culturally acceptable to native populations and outlines “next steps.” **Abstract:** <https://goo.gl/kz1H9S>



N.B. Click on pdf icon to access full text.

Noted in Media Watch 7 May 2018 (#562, p.12):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2018;24(4):160-168. ‘**Addressing palliative and end-of-life care needs with Native American elders.**’ Life-limiting illness plagues Native Americans, yet access to palliative and end-of-life care, including hospice care, is severely limited. This study aimed to explore palliative and hospice care with Native American elders and tribal health educators on a Northern Plains reservation in the U.S. Opportunities were present for improving cultural awareness and advance directive education to elders. Challenges raised were related to infrastructure, tribal government, and the Indian Health Service. **Abstract:** <https://goo.gl/Ssl3AA>

N.B. Additional articles on palliative and end-of-life care for U.S. indigenous populations noted in this issue of Media Watch.

Ambiguity, death determination, and the dead donor rule

CLINICAL ETHICS | Online – 26 July 2018 – The dead donor rule states that organ donors must be declared dead before any vital organs are removed. Recently, scholars and physicians have argued for the abandonment of the dead donor rule, based on the rule’s supposed connection with the concept of brain death, which they view as a conceptually unreliable definition of death. The author of this article distinguishes between methods of death determination and the question of whether or not the dead donor rule should be a guiding principle of organ transplant ethics. In principle, the dead donor rule does not rely on any one definition of death, but only prohibits the taking of vital organs before a patient is declared dead. In light of this distinction, he argues that even if the dead donor rule is tied to brain death in practice, conceptual disagreement about brain death does not provide grounds for rejection of this rule. The author presents evidence in support of the consistency and reliability of the diagnosis of brain death. He shows that, when performed carefully and under specific clinical circumstances, the diagnosis of brain death is considered by most neurologists to be reliable. Finally, the author argues that, without the dead donor rule, organ transplantation programs would become susceptible to violations of the ethical principle of respect for persons. **Abstract:** <https://goo.gl/aKgPjh>

Cont.

Noted in Media Watch 26 March 2018 (#556, p.12):

- *JOURNAL OF CLINICAL ETHICS*, 2018;29(1):31-42. ‘**An international legal review of the relationship between brain death and organ transplantation.**’ The “dead-donor rule” states that in any case of vital organ donation the potential donor should be determined to be dead before transplantation occurs. In many countries around the world, neurological criteria can be used to legally determine death (also referred to as brain death). Nevertheless, there is considerable controversy in the bioethics literature over whether brain death is the equivalent of biological death. This international legal review demonstrates that there is considerable variability in how different jurisdictions have evolved to justify the legal status of brain death and its relationship to the dead-donor rule. **Abstract:** <https://goo.gl/sKvahu>

N.B. Additional articles on defining “brain dead” noted in the 26 February 2018 and 20 November 2017 issues of Media Watch (#552, p.2 and #539, p.1, respectively).

End of life, withdrawal, and palliative care utilization among patients receiving maintenance hemodialysis therapy

CLINICAL JOURNAL OF THE AMERICAN SOCIETY OF NEPHROLOGY | Online – 19 July 2018 – Withdrawal from maintenance hemodialysis before death has become more common because of high disease and treatment burden. This study’s objective was to identify patient factors and examine the terminal course associated with hemodialysis withdrawal, and assess patterns of palliative care (PC) involvement before death among patients on maintenance hemodialysis. Among 1,226 patients, 536 died and 262 withdrew. A random sample review of Death Notification Forms revealed 73% sensitivity for withdrawal. Risk factors for withdrawal before death included older age, white race, PC consultation within 6 months, hospitalization within 30 days, cerebrovascular disease, and no coronary artery disease. Most withdrawal decisions were made by patients (60%) or a family member (33%; surrogates). The majority withdrew either because of acute medical complications (51%) or failure to thrive/frailty (22%). After withdrawal, median time to death was 7 days... In-hospital deaths were less common in the withdrawal group... A third of those that withdrew received PC services. PC consultation in the withdrawal group was associated with longer hemodialysis duration..., hospitalization within 30 days of death ..., and death in hospital... In this single-center study, the rate of hemodialysis withdrawals were twice the frequency previously described. Acute medical complications and frailty appeared to be driving factors. However, PC services were used in only a minority of patients. **Abstract (w. “visual overview”):** <https://goo.gl/NfgnRn>

N.B. Editorial on ‘Meeting the palliative care needs of maintenance hemodialysis patients: Beyond the math,’ also posted on the journal’s website at: <https://goo.gl/uXhLwr>

Noted in Media Watch 25 June 2018 (#569, pp.8-9):

- *AMERICAN JOURNAL OF KIDNEY DISEASES* | Online – 16 June 2018 – ‘**End-stage renal disease and hospice care in the U.S.: Are dialysis patients welcome?**’ Although the dialysis population has changed markedly, hospice has not changed to accommodate dialysis. Hospice is set in its ways, insisting on doing things the way they have always been done. Take it or leave it. And if you take it, many hospice programs will insist that one leaves dialysis therapy. However, the hospice philosophy is but one piece of the puzzle, with the full picture including policy driven by cost. National policy currently restricts access to hospice care to patients with kidney failure who either forego or withdraw from dialysis therapy. **Full text:** <https://goo.gl/j3HyJj>

N.B. Additional articles on palliative care for people receiving maintenance hemodialysis in the U.S. noted in this issue of Media Watch.

Cont. next page



Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8l>

Noted in Media Watch 9 April 2018 (#558, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 April 2018 – ‘**Ten tips nephrologists wish the palliative care team knew about caring for patients with kidney disease.**’ Many patients with chronic kidney disease (CKD) and end-stage renal disease (ESRD) have unmet palliative care (PC) needs. Physical and emotional symptoms are common. Some improve with dialysis, but the increasing age of patients initiating renal replacement therapy leaves many untreatable co-morbidities, like dementia and frailty to negatively impact quality of life. This article will help PC providers to have a richer understanding of kidney disease-related symptom burden, disease trajectory, prognosis, and barriers to hospice enrollment for patients with CKD and ESRD. **Abstract:** <https://goo.gl/ZETT6G>

Supporting self-management in palliative care throughout the cancer care trajectory

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 20 July 2018 – Recent studies provide evidence of support among patients, family caregivers and healthcare professionals for integration of self-management interventions into palliative cancer care. As a guiding framework, components of the revised Self & Family Management Framework correspond to the provision of palliative care (PC) across the care trajectory, including the phases of curative care, PC, end-of-life care and bereavement. Additional work among self-management partners facing cancer and other life-limiting illnesses, that is patients, family caregivers and healthcare professionals, would be useful in developing interventions that incorporate self-management and PC to improve health outcomes. **Abstract:** <https://goo.gl/4GsKn5>

Noted in Media Watch 29 October 2012 (#277, p.8):

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2012;18(10):471. ‘**Shifting dying trajectories: Integrating self-management and palliative care.**’ For access options: <https://goo.gl/iqSfBY>

Patient and caregiver involvement in formulation of guideline questions: Findings from the European Academy of Neurology Guideline on Palliative Care of People with Severe Multiple Sclerosis

EUROPEAN JOURNAL OF NEUROLOGY | Online – 23 July 2018 – Patient and public involvement in clinical practice guideline development is recommended to increase guideline trustworthiness and relevance. Of 1,199 participants, 79% completed the online survey, and 934 from seven countries were analyzed: 80% were multiple sclerosis (MS) patients (74% women, mean age 46.1) and 183 (20%) caregivers (36% spouses/partners, 72% women, mean age 47.4). Participants agreed/strongly agreed on inclusion of the nine pre-specified topics (from 89% for “advance care planning” to 98% for “multidisciplinary rehabilitation”), and 5% replied “I prefer not to answer” to any topic. There were 569 free comments: 32% on the pre-specified topics, 40% on additional topics (16 guideline-pertinent), and 160 (28%) on outcomes. Five focus group meetings (three of MS patients, two of caregivers, overall 35 participants) corroborated the survey findings. In addition, they allowed the explanation of the guideline production process, the exploration of patient-important outcomes and of taxing issues. MS patient and caregiver involvement was resource and time intensive, but rewarding. It was key for the formulation of the 10 guideline questions, and for the identification of patient-important outcomes. **Abstract:** <https://goo.gl/18J9hY>

Noted in Media Watch 2 July 2018 (#570, p.12):

- *MEDSCAPE* | Online – 26 June 2018 – ‘**New European Academy of Neurology guideline on palliative care in multiple sclerosis.**’ Delegates to the Congress of the European Academy of Neurology 2018 discussed palliative care (PC) as it relates to neurology in general – but also in the setting of multiple sclerosis (MS) in particular – as a guideline targeted to patients with severe MS was discussed. The new MS guideline [yet to be published] emphasizes the need for a multidisciplinary and multi-professional approach to care. For example, a PC team could include a neurologist, a nurse, a physiotherapist, and a social worker. **Full text:** <https://goo.gl/uKKNrd>

N.B. Selected articles on palliative care for people living with multiple sclerosis noted in the 17 October 2016 issue of Media Watch (#483, p.12).

Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life

HEALTH & PLACE, 2018;53(9):43-51. The process of dying pronounces inequities, particularly for structurally vulnerable populations. Extending recent health geography research, the authors critically explore how the “places” of formal healthcare settings shape experiences of, and access to, palliative care (PC) for the structurally vulnerable (e.g., homeless, substance users). Drawing on 30 months of ethnographic data, thematic findings reveal how symbolic, aesthetic and physical elements of formal healthcare “places” intersect with social relations of power to produce, reinforce, and amplify structural vulnerability and thus, inequities in access to care. Such knowledge may inform decision-makers on ways to enhance equitable access to PC for some of societies’ most vulnerable... **Abstract:** <https://goo.gl/yVe7gE>

An ethical framework for the creation, governance and evaluation of accelerated access programs

HEALTH POLICY | Online – 20 July 2018 – There are increasing demands on regulators and insurers internationally to provide access to medicines more quickly, and often on the basis of less robust evidence of safety, efficacy or cost-effectiveness than have traditionally been required. These demands arise from a number of sources, including those advocating for access to medicines for patients with life-threatening diseases, rare diseases, or subsets of common diseases and where entire populations are threatened in the context of public health emergencies. In response to these demands, policymakers have instituted a number of initiatives aimed at speeding up access to medicines, which we refer to collectively as “accelerated access” programs. While there are strong arguments for accelerated access programs, these programs also raise a number of socio-political, epistemic and moral issues. Some of these issues are common to all types of accelerated access programs, while others are specific to particular types of accelerated access. The authors offer a conceptual framework that highlights ethically relevant similarities and differences among different kinds of accelerated access processes for the purpose of enabling ethically and politically-informed policy making. **Abstract (w. link to references):** <https://goo.gl/9LFckt>

N.B. Selected articles on the issue of “right-to-try” new experimental or investigational drugs noted in the 11 June 2018 issue of Media Watch (#567, p.12).

Origins and effects of the 2014-2016 National Strategy for Palliative Care in Croatia

HEALTH POLICY | Online – 20 July 2018 – Croatia is among the last countries in Europe to develop organized palliative care (PC) at the national level. Real changes in this area started after the parliamentary elections in 2011 and culminated in the 2013 adoption of the Strategic Plan for Palliative Care Development 2014-2016. The National Board for Palliative Care, appointed by the Ministry of Health, was in charge of creating a scalable PC model and national guidelines. The Board drew on experiences from both neighbouring countries with similar societies and/or health care models (Bosnia and Herzegovina, Poland) and an international leader in PC (U.K.). It recognised that provision of PC in Croatia, thus far based on volunteering and isolated enthusiastic activities, needed to be improved through professionalization, regulation, and organized development. A variety of policy measures was used to implement these changes, including the introduction of professional guidelines and new payment models. The development of new PC structures and services significantly increased the number of patients who could access PC, from around 1-2% of patients needing such care in 2011 to 20-35% in 2014. It also ensured the provision of more appropriate services at each point of the PC pathway. The Strategy was extended for the 2017-2020 period. **Full text:** <https://goo.gl/Fmtudv>

N.B. Additional articles on the development of palliative care in Croatia noted in the 27 March 2017 issue of Media Watch (#505, p.13).



Media Watch: Behind the Scenes
<http://goo.gl/XDiHxz>

A systematic review of the use of the electronic health record for patient identification, communication, and clinical support in palliative care

JAMIA OPEN | Online – 6 July 2018 – The results of the studies presented in this system review contributed to the relevant understanding of the importance of early patient identification for palliative care (PC), patient reporting, PC summaries, advance care planning (ACP), communication, and electronic health record (EHR) enhancement for PC. The variation of methodology used in these studies resulted in one common and consistent theme, which is the EHR has yet to be optimized for its potential contributions to PC. Nevertheless, recent approaches of clinical decision support (CDS) and patient-reported outcome measures (PROMs) demonstrated the EHR can be used to facilitate PC and to potentially result in improved PC, as well as a better quality of life for patients and their families. Patient-reported outcomes, such as pain levels and discomfort benefit the care team, helping to change treatment course and improve patient comfort. Further studies of the role of CDS and PROMs to identify appropriate patients, establish care goals earlier in their illness as well as the potential to reduce provider discomfort when introducing the topics of PC, ACP, death, and dying are needed. Earlier and more effective PC identification can also help providers, patients, and families to discuss end-of-life (EoL) options to match with the best type of care according to patient goals and EoL stage, improving comfort care and allowing provider to focus on offering the best intervention. **Full text:** <https://goo.gl/8K7REJ>

Noted in Media Watch 19 September 2016 (#480, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 September 2016 – ‘**Crash course in Electronic Palliative Care Coordination Systems: 8 years of successes and failures in patient data sharing to learn from.**’ Electronic Palliative Care Coordination Systems (EPaCCS) are England’s pre-eminent initiative in enabling advance care planning and improved communication and coordination at the end of life. EPaCCS are electronic registers or tools and processes for sharing data which aim to enable access to information about dying patients. Striking outcomes have been reported around EPaCCS, such as 77.8% of ‘Coordinate My Care’ patients dying in their preferred place. EPaCCS have, however, been extremely challenging to develop and implement, with many projects remaining continuously “under development” or folding. **Full text:** <https://goo.gl/ao50pL>

Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services

JOURNAL OF ADVANCE NURSING | Online – 25 July 2018 – In this study, six conflicting realities were identified: 1) Planning to live and planning to die with different illness trajectories that misaligned with adult service models; 2) Being treated as an adult and the oldest “patient” in children’s services compared with being treated as a child and the youngest “patient” in adult services; 3) Being a “child” in a child’s body in children’s services compared with being a “child” in an adult’s body in adult services for those with learning impairments; 4) Being treated by experienced children’s professionals within specialist children’s services compared with being treated by relatively inexperienced professionals within generalist adult services; 5) Being relatively one of many with the condition in children’s services to being one of very few with the condition in adult services; and, 6) Meeting the same eligibility criteria in children’s services but not adult services. Inequity and skills deficits can be addressed through targeted interventions. Expanding age-specific transition services, use of peer-to-peer social media, and greater joint facilitation of social support groups between health services and not-for-profit organisations may help mitigate age dilution and social isolation in adult services. **Advance:** <https://goo.gl/G6QnJB>

Related

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2018;24(7):322-332. ‘**Evaluation of a pilot service to help young people with life-limiting conditions transition from children’s palliative care services.**’ When young people with life-limiting diagnoses become too old for children’s hospice services, they often experience challenges transitioning into adult services. A two-year pilot project was developed to try to aid transitioning, which involved a day service with occasional overnight trips. This pilot models a service that could be adopted by other organisations in order to aid the transition between child and adult hospice services, with further potential for application in mental health and special needs services. **Abstract:** <https://goo.gl/UjL9nQ>

Should emergency department patients with end-of-life directives be admitted to the ICU?

JOURNAL OF EMERGENCY MEDICINE | Online – 24 July 2018 – The authors discuss the interplay between clinical indications, patient preferences, and advance care directives, and make recommendations about what the emergency physician must consider when deciding whether a patient with an advance care planning document should be admitted to the ICU. Although some patients may wish to avoid certain aggressive or invasive measures available in an ICU, there may be a tendency, reinforced by recent Society of Critical Care Medicine guidelines, to presume that such patients will not benefit as much as other patients from the specialized care of the ICU. The ICU still may be the most appropriate setting for hospitalization to access care outside of the limitations set forward in those end-of-life care (EoL) directives. On the other hand, ICU beds are a scarce and expensive resource that may offer aggressive treatments that can inflict suffering onto patients unlikely to benefit from them. Goals-of-care (GoC) discussions are critical to align patient EoL preferences with hospital resources, and therefore, the appropriateness of ICU disposition. EoL care directives should not automatically exclude patients from the ICU. Rather, ICU admission should be based upon the alignment of uniquely beneficial treatment offered by the ICU and patients' values and stated GoC. **Abstract (w. link to references):** <https://goo.gl/W3jjPQ>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 July 2018 – '**Expanding goals-of-care conversations across a health system: The mapping the future program.**' Small-scale educational interventions have demonstrated improvement in physician communication skills, but it is unknown if these results translate into practice changes. In 2017, the authors trained 512 clinicians in 42 sessions. After the course, participants felt that they had improved in all the skills that were taught and agreed that they would be more likely to initiate goals of care conversations. **Abstract (w. link to references):** <https://goo.gl/VzkXYe>
- *JAMA ONCOLOGY* | Online – 26 July 2018 – '**Effect of a lay health worker intervention on goals-of-care documentation and on health care use, costs, and satisfaction among patients with cancer.**' Can an outpatient lay health worker intervention improve end-of-life (EoL) care for patients with cancer? In this randomized clinical trial of 213 veterans with stage 3 or 4 or recurrent cancer, a lay health worker intervention significantly increased documentation of patients' EoL care preferences. **Abstract:** <https://goo.gl/jdt8R7>

Recent insights into decision-making and their implications for informed consent

JOURNAL OF MEDICAL ETHICS | Online – 21 July 2018 – Research from behavioural sciences shows that people reach decisions in a much less rational and well-considered way than was often assumed. The doctrine of informed consent, which is an important ethical principle and legal requirement in medical practice, is being challenged by these insights into decision-making and real-world choice behaviour. This article discusses the implications of recent insights of research on decision-making behaviour for the informed consent doctrine. It concludes that there is a significant tension between the often non-rational choice behaviour and the traditional theory of informed consent. Responsible ways of dealing with or solving these problems are considered. To this end, patient decisions aids (PDAs) are discussed as suitable interventions to support autonomous decision-making. However, current PDAs demand certain improvements in order to protect and promote autonomous decision-making. Based on a conception of autonomy, we will argue which type of improvements are needed. **Abstract:** <https://goo.gl/BhLx9r>

Effects of caregiver and decedent characteristics on Consumer Assessment of Healthcare Providers & Systems (CAHPS) Hospice Survey scores

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 July 2018

– The CAHPS Hospice Survey assesses the care experiences of hospice patients and their families. Public reporting of hospice performance on these survey measures began in February 2018. The authors analyzed survey data reflecting experiences of 915,442 patients who received care from 2,513 hospice programs between April 2015 and March 2016. Decedent and caregiver characteristics were identified for inclusion in case-mix adjustment based on their variation across hospices ... and how predictive they were of responses to survey questions... The final case-mix adjustment model included decedent age, payer for hospice care, primary diagnosis, length of final episode of hospice care, caregiver age, caregiver education, relationship to decedent, survey language/language spoken at home, and response percentile. To ensure fair comparisons across hospices, CAHPS Hospice Survey measure scores should be adjusted for several caregiver and decedent characteristics. **Abstract (w. link to references):** <https://goo.gl/CDV9cN>



Gratitude at the end of life: A promising lead for palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 25 July 2018 – Numerous studies, conducted largely with non-clinical populations, have shown a significant link between gratitude and psychological dimensions relevant for palliative care (PC), e.g., psychological distress. However, the relevance of gratitude in the context of PC needs to be confirmed. Sixty-four patients participated in this exploratory and cross-sectional study. The results showed significant positive correlations between gratitude and quality of life (QoL), and the appreciation of life dimension of the post-traumatic growth. Significant negative correlations were found between gratitude and psychological distress, and health status. The best model for QoL explained 47.6% of the variance and included psychological distress and gratitude. The relational dimension was the most frequently cited source of gratitude. Gratitude may act positively on QoL and may protect against psychological distress in the palliative situation. The next step will be the adaptation and implementation of a gratitude-based intervention. **Abstract:** <https://goo.gl/wqbaev>

The construction of physician-patient trust. A case report of an oncologist's consults in palliative care

LINGUE CULTURE MEDIAZIONI, 2018;5(1):101-111. Bioethical issues are often related to medical decisions regarding life and death. Those decisions (e.g., the chosen treatment, palliative care, euthanasia) are taken by patients in consultation with their families, their physician and other medical personnel. It is of the utmost importance that discussions of such an importance take place in a climate of confidence: the patients need to trust that the physician will advise them on the best course to take. In this paper an overview of twelve follow-up visits in palliative context was presented, focussing on one of them as an exemplary case. It was demonstrated how the oncologist presents himself as a trustworthy person: he shows his medical, communicative and social competence, and his personal characteristics, such as his empathetic attitude, add to the trust building. Some linguistic strategies that create trust were illustrated. Hyde and King (2010) state that we can only get a full grip on the complex matter of society and bioethics if different groups of society join forces. They refer to policymakers, scholars, scientists and the public. This paper has shown that also discourse analysis and applied linguistics can contribute to this discussion. **Extract (inc. list of references):** <https://goo.gl/yJwrG4>

N.B. English language article. Click on pdf icon to access full text.



Supporting Grieving or Bereaved Children
<http://goo.gl/ydHfq9>

The impact of unusual end-of-life phenomena on hospice palliative care volunteers and their perceived needs for training to respond to them

OMEGA – JOURNAL OF DEATH & DYING | Online – 22 July 2018 – Thirty-nine hospice palliative care volunteers completed a survey examining: a) Their beliefs about end-of-life phenomena (EoLP); b) The impact of EoLP on their lives; and c) Their perceived needs for training to respond to them. Forty-nine percent of the volunteers either had personally witnessed an EoLP in their volunteer work and/or had a patient or patient's family member report an EoLP to them. More than half of the volunteers strongly agreed or agreed that EoLP have influenced their religious beliefs and their spirituality in a positive way (53% and 59%, respectively). Eighty-nine percent of the volunteers indicated that they had never received any training about EoLP, and nearly all of the volunteers were interested in learning more about EoLP. After completing the survey, 59% of the volunteers shared stories about EoLP they had either personally witnessed or been told about. The most frequently reported experiences involved deathbed visions. The implications of these findings are discussed. **Abstract:** <https://goo.gl/piLNZ1>

Noted in Media Watch 5 September 2016 (#478, p.15):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 1 September 2016 – ‘**Hospice palliative care volunteers’ experiences with unusual end-of-life phenomena.**’ The most commonly witnessed end-of-life phenomena were patients talking to or reaching out their hands toward deceased relatives or friends, occurrences of terminal lucidity, and patients seemingly getting ready for a trip or journey. At least a third of the volunteers [i.e., survey respondents] indicated that a patient or a patient's family member had told them about visions or dreams of deceased relatives or friends, seeing beautiful places or colors or hearing wonderful music, terminal lucidity, and deathbed coincidences. **Abstract:** <http://goo.gl/UV74Xg>

Willingness to participate in HIV research at the end of life

PLOS ONE | Online – 23 July 2018 – The authors call for a broad, frank, and pragmatic discussion about research near the end of life (EoL), which may represent a new, innovative paradigm in how we conduct research with human participants (“less to lose” versus “otherwise healthy volunteers”). In this dialogue, they envision that cultural, ethical and legal challenges can be resolved, and that research safeguards can be developed. Research in this setting offers a valuable alternative to animal testing which is more generalizable to the human condition, and allows those who are dying one more chance to give to future generations. We must tackle the cultural, ethical and infrastructure barriers that prevent people from participating in clinical research at the EoL to help overcome many of the important health challenges of our day. **Full text:** <https://goo.gl/ynixNx>

Family caregiver descriptions of stopping chemotherapy and end-of-life transitions

SUPPORTIVE CARE IN CANCER | Online – 28 July 2018 – The authors identify three patterns of transitions characterizing the shift away from active cancer treatment: 1) “We pretty much knew,” characterized by explicit discussions about end-of-life (EoL) care, seemingly shared understanding about prognosis and seamless transitions from disease-oriented treatment to comfort-oriented care; 2) “Beating the odds,” characterized by explicit discussions about disease-directed treatment and EoL care options, but no shared understanding about prognosis and often chaotic transitions to EoL care; and, 3) “Left to die,” characterized by no recall of EoL discussions with transitions to EoL occurring in crisis. As communication and palliative care interventions continue to develop to improve care for patients with advanced cancer, it is imperative that we take into account the different patterns of transition and their unique patient and caregiver needs near the EoL. **Abstract (inc. list of references):** <https://goo.gl/EPZp83>



Prison Hospice: Backgrounder

End-of-life care in the prison system has been high-lighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (updated 1 May 2018) can be downloaded/viewed at: <https://goo.gl/YLckx6>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2018;24(7): 333-337. **‘The Belgian euthanasia law and its impact on the practises of Belgian paediatric palliative care teams.’** In 25 Years of clinical practice, Belgian paediatric palliative care (PC) teams expressed that they were never confronted with a child requesting euthanasia. If parental requests for hastening death were observed, they were often caused by intense despair or a feeling of being overburdened. Once the child’s intense physical pain was managed and the parents’ fears listened to, those requests generally disappeared. However, in Belgium in February 2014, an existing euthanasia law for adults was extended to minors. Values such as compassion and humanity were cited as reasons to support the extension of the law to minors. Since the law was extended to minors, euthanasia has been granted for two adolescents... Both individuals had first received PC in their last stage of life. **First page view:** <https://goo.gl/pDjBiP>
- *JOURNAL OF MEDICAL ETHICS* | Online – 21 July 2018 – **‘When slippery slope arguments miss the mark: A lesson from one against physician-assisted death.’** In 1989, [American philosopher] Susan Wolf convincingly warned of a troublesome consequence that should discourage any movement in American society towards physician-assisted death – a legal backlash against the gains made for limiting life-sustaining treatment. The authors demonstrate that this dire consequence did not come to pass. As physician-assisted suicide gains a foothold in the U.S. and elsewhere, many other slippery slope arguments are being put forward. Although many of these speculations should be taken seriously, they do not justify halting the new practice. Instead, our courts, regulatory agencies, journalists, professional organisations and researchers should carefully monitor and study it as it unfolds, allowing continuous improvement just as our society has done in implementing the practice of limiting life-sustaining treatment. **Abstract:** <https://goo.gl/vCKKa6>
- *VIA PANORAMICA: REVISTA DE ESTUDOS ANGLO-AMERICANOS*, 2018;7(1):49-58. **‘From sin to treatment: A very brief survey of the relationship between political power and end-of-life decisions in Western societies.’** Death and the circumstances under which one dies have been one of the most prolific themes in literature, the arts, and science in Western societies. Up until now, end-of-life practices in the West have relied more on curative treatments than on palliative care. The legalization of intentional practices such as euthanasia and assisted-suicide, in particular, is still a highly controversial topic. All this may lead us to think that the preservation of life and the intrinsic value of human beings inform current medical and political paradigms. **Full text:** <https://goo.gl/3VHkWc>

N.B. English language article.

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.

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

[Something Missed or Overlooked?](#)

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

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[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

Asia

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Australia

PALLIATIVE CARE WESTERN AUSTRALIA: <https://goo.gl/fCzNTL>

[Scroll down to 'International Websites']

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/gw5ti8>

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']



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

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

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>

[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

SASKATCHEWAN | Saskatchewan Medical Association: <https://goo.gl/5cftPV>

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Europe



EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/KjrR6F>

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/L7D2hw>

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

South America



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

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