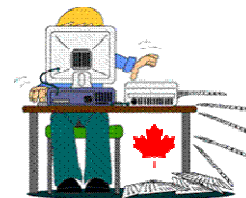


## Media Watch...

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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Compilation of Media Watch 2008-2016 ©

Compiled & Annotated by Barry R. Ashpole

At the frontline: Scroll down to [Specialist Publications](#) and 'Caring for dying patients in the nursing home: Voices from frontline nursing home staff' (p.9), in *Journal of Pain & Symptom Management*.

## Canada

### Terminally ill patients campaign for "right-to-try" treatments

*THE OTTAWA CITIZEN* | Online – 3 November 2016 – A group of patients with terminal illnesses is urging MPs to give them the "right-to-try" unapproved treatments. There are 28 members of the group, all with amyotrophic lateral sclerosis (ALS) or terminal cancer, said Right-to-Try co-founder Jeffrey Perrault. The group sent emails to all MPs ... asking for legislation that would give dying patients access to potentially life-saving and life-lengthening treatments and drugs that are not approved by Health Canada. If a competent person with an incurable illness leading to a foreseeable death can consent to medically-assisted death, that same person should have the right to seek treatment that does not have Health Canada approval, said Perrault... According to the group's proposal, patients who are eligible for the "right-to-try" would need to have a terminal illness and have tried all other treatment options already approved by Health Canada. The patient would have to give informed consent to treatment using an unapproved therapy, and would also need the approval of a physician. Health Canada's special access program allows doctors access to drugs and medical devices that have not yet been approved for sale in Canada to treat patients with serious or life-threatening conditions when conventional therapies have failed, or if they are unsuitable or unavailable. <https://goo.gl/lKKRNq>

#### Selected articles on the "right-to-try" laws

- *BMC MEDICAL ETHICS* | Online – 18 October 2016 – '**An analysis of common ethical justifications for compassionate use programs for experimental drugs.**' In this paper the arguments given in favour of compassionate use or expanded access programs have been put into three broad categories. [Noted in Media Watch 24 October 2016, #484 (p.6)] <https://goo.gl/jHLAey>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 11 February 2016 – '**The ethical challenges of compassionate use.**' Granting access to drugs, vaccines, biologics, and devices not yet approved by governmental regulatory authorities is a growing challenge for physicians, public officials, patient advocacy groups, institutional review boards, and patients. [Noted in Media Watch 22 February 2016, #450 (p.12)] <http://goo.gl/Llu1iO>
- *ANNALS OF INTERNAL MEDICINE* | Online – 29 September 2015 – '**Right-to-try laws: Hope, hype, and unintended consequences.**' Most "right-to-try" laws do not set qualifications for either the health care provider making attestation of terminal illness or the physician recommending experimental treatment. [Noted in Media Watch 5 October 2015, #430 (p.7)] <http://goo.gl/JWifuy>

## How to improve palliative care in Canada: A call to action for federal, provincial, territorial, regional and local decision makers

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS (CSPCP) | Online – 2 November 2016 – The Society is calling on politicians at all levels of government to act immediately to improve access to palliative care (PC) in Canada. “With attention focused on developing a new health accord between the federal government and the provinces and territories on health care there is no better time to address serious deficiencies in the care provided to patients requiring PC,” said CSPCP President Dr. David Henderson... In its new report ... the CSPCP provides a detailed set of recommendations on how decision-makers can move to address serious deficiencies in the existing system. PC is the health discipline which focuses on improving the quality of life of people living with life-threatening illness and includes, but is not limited to, end-of-life care. Currently only one in three Canadians has access to specialized PC services. The Federal government has committed funds for home care and PC without an implementation plan or commitment to universal access. Canadians now have the right to access medical assistance in dying. We need a similar right to access PC. <https://goo.gl/DiBjDx>



Noted in Media Watch 6 June 2016, #465 (p.3):

- RADIO CANADA INTERNATIONAL | Online – 30 May 2016 – ‘**Doctors urge improvement in end-of-life care.**’ The Canadian Society of Palliative Care Physicians says ... there is a lack of palliative care (PC) service and it is unevenly distributed, says Dr. David Henderson, president of the society. In Canada, the central government provides guidelines on health services and funding, but the provinces and territories manage them. PC doctors would like to see one body set up to decide what are best practices in PC, how to mobilize them and set standards, and to collect data. <http://goo.gl/GKnk5z>

**N.B.** Nine key studies on access to palliative care in Canada, published between 1995 and 2014, are listed in Media Watch 22 December 2014, #389 (p.4). In December 2015, the Canadian Cancer Society published ‘Right to Care: Palliative Care for all Canadians.’ [Noted in Media Watch 18 January 2016, #445 (p.1)] <http://goo.gl/f3iFEB>

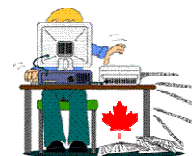
### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *The Ottawa Citizen* – 3 November 2016 – ‘**Ontario adds wording to legislation recognizing conscience rights of hospitals.**’ The Ontario government has quietly amended its proposed Patients First Act with wording that appears to strengthen the rights of faith-based hospitals to opt out of assisted death. The proposed amendment, which was not originally in the act, appeared when it was re-tabled last month after the legislature was prorogued. The act amends part of the existing Public Hospital Act in a way that gives the health minister additional powers to give directives to hospital boards. In the revised act reintroduced in early October there is an added caveat that any directives issued by the health minister to hospital boards: “Shall not unjustifiably as determined under section 1 of the Canadian Charter of Rights and Freedoms require the board of a hospital that is associated with a religious organization to provide a service that is contrary to the religion related to the organization.” <https://goo.gl/tdGgTv>

### [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>



## U.S.A.

### **The way doctors give patients bad news can teach us all something about how to have hard conversations**

QUARTZ | Online – 3 November 2016 – It's not uncommon for Andrew Epstein to spend sleepless nights replaying scenes from his day and wondering what more he could have done for his patients. Often, the answer is nothing – but that still doesn't help his insomnia. Epstein is an oncologist at the Sloan Kettering Memorial Cancer Center... His job requires conversations with patients who are extremely sick. Sometimes, he's breaking the news of the severity of their illness to them; other times, he's telling them the treatment they thought may work has failed, and it's time to begin preparing for end-of-life care. Each encounter is so emotionally draining, he can only do it for about half of the week; he spends the rest of his time preparing for future conversations with new patients, or recovering. Telling patients and their families that they must face their own mortality is one of the most difficult things that has to get done in the medical profession. Most patients want to have conversations about care at the end of their lives, but often don't end up having them – probably because many doctors are not prepared to do so, despite training as part of medical school. <https://goo.gl/zZLx03>

#### Specialist Publications

**'Factors associated with patient preferences for communication of bad news'** (p.11), in *Palliative & Supportive Care*.

### **At end of life in Massachusetts hospital care is big cost**

MASSACHUSETTS | *The Boston Globe* – 2 November 2016 – When death approaches, most people would rather spend their days at home. But in Massachusetts, a remarkable number of dying patients often end up in hospital beds instead, and enter hospice for only a few days, a new analysis has found. Massachusetts, especially the eastern part of the state, ranks among the lowest in the nation for the number of days residents spend at home during their final six months. Nearly one-fourth die in hospitals – a sign of the reluctance in the medical establishment to use hospice or palliative. Medicare spent more money on hospital care in Massachusetts than on any other health service in patients' last six months of life, according to a study by the Health Policy Commission, a state agency that monitors medical costs. Two-thirds of patients endured hospitalization during their final half-year, with an average stay of 12 days. In Massachusetts, Medicare spent nearly \$40,000 per patient in the last six months of life, for a total of more than \$1 billion. But 42% went to inpatient hospital care, with 11% paying for hospice and only 4% for home health care. The study looked only at Medicare, which pays for most of the health care received by people 65 and older. It did not account for contributions by private insurance or the state Medicaid program, which covers nursing home care and some home health services. <https://goo.gl/ygWxT0>

#### Specialist Publications

**'Medicare and end-of-life care'** (p.7), in *Journal of the American Medical Association*.

**'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline updated'** (p.8), in *Journal of Clinical Oncology*.

**'A critical "P" in patient-centered care: Palliative care for all of us'** (p.8), in *Journal of Continuing Education in Nursing*.

## Quarter of seniors don't discuss end-of-life care

UNITED PRESS INTERNATIONAL | Online – 31 October 2016 – More than one-quarter of American seniors have never discussed end-of-life (EOL) care, a new study finds.<sup>1</sup> “Despite decades of work to improve advance care planning (ACP), over a quarter of older adults have still not engaged in any type of discussion or planning for their EOL preferences or plans,” said lead author Krista Harrison, a geriatrics research fellow at the University of California, San Francisco. More than one-quarter of American seniors have never discussed EOL care, a new study finds. “Despite decades of work to improve ACP, over a quarter of older adults have still not engaged in any type of discussion or planning for their EOL preferences or plans,” said lead

author Krista Harrison, a geriatrics research fellow at the University of California, San Francisco. <https://goo.gl/g4lbqU>

### Specialist Publications

**‘Racial differences in associations of perceived health and social and physical activities with advance care planning, end-of-life concerns, and hospice knowledge’** (p.10), in *American Journal of Hospice & Palliative Medicine*.

**‘The quality of Physician Orders for Life-Sustaining Treatment (POLST) decisions: A pilot study’** (p.10), in *Journal of Palliative Medicine*.

1. ‘Low completion and disparities in advance care planning activities among older Medicare beneficiaries,’ *JAMA Internal Medicine*, 31 October 2016. <https://goo.gl/lKe1yC>

### Selected articles on advance care planning in the U.S.

- *ADVANCES IN NURSING SCIENCE* | Online – 11 August 2016 – **‘Facing death: A critical analysis of advance care planning in the U.S.’** The rates of advance care plans (ACPs) are low and physicians, as the primary gatekeepers, have made little progress in improving their rates. The authors examined these forces and identify the ideologies, assumptions, and social structures that curtail completion of ACPs such as preserving life, ageism, paternalism, and market-driven healthcare system. [Noted in Media Watch 22 August 2016, #476 (p.7)] <http://goo.gl/lfWrB>
- *JOURNAL OF PATIENT-CENTERED RESEARCH & REVIEWS*, 2016;3(3):167-168. **‘Advance care planning practices in caring for vulnerable elders: An analysis of electronic health record data and interviews with physicians.’** Among those with serious illness [i.e., patients interviewed], at the end of two years only 21.13% had an advance care plan (ACP). Interviewees suggested three stages of ACP: 1) Initial patient-physician conversations; 2) Patient investigates/discusses with family; and, 3) Follow-up with physician. [Noted in Media Watch 22 August 2016, #476 (p.7)] <http://goo.gl/sW5Kbv>
- *HEC FORUM* | Online – 8 July 2016 – **‘Failure of the current advance care planning paradigm: Advocating for a communications-based approach.’** The intersection of end-of-life (EOL) medical technology, ethics of EOL care, and state and federal law has driven the development of the legal framework for advance directives (ADs). From an ethical perspective the current legal framework is inadequate to make ADs an effective EOL planning tool. [Noted in Media Watch 11 July 2016, #470 (p.13)] <http://goo.gl/QvZLSo>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- WASHINGTON DC | *The Washington Post* – 1 November 2016 – **‘DC Council gives initial approval to a bill to let terminally ill patients end their lives.’** The DC Council ... gave initial approval to legislation that would allow physicians to prescribe fatal drugs to terminally ill residents in the city, making the District the sixth jurisdiction nationwide to allow the practice. It is the first predominantly black community to legalize so-called “death with dignity,” overcoming objections from some African American residents. The council still must hold a final vote on the bill... <https://goo.gl/rYGvW5>

## International

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

#### **Palliative care warning: GPs only have “TEN minutes” to care for terminally-ill patients**

U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Express* – 3 November 2016 – GPs do not have the time they would like to support patients with a terminal illness – with new figures revealing some doctors only have ten minutes available to talk to dying patients. A new U.K.-wide survey from the Royal College of General Practitioners (RCGP) and Marie Curie has revealed 83% of GPs said giving more time to terminally ill patients was a top priority, but many said that they lacked the time and resource to deliver it. GPs said that they would ideally like more time than they currently have with patients and families, and particularly for those who are able to visit their surgeries. While the majority of GPs – 71% – thought that over 20 minutes should ideally be allocated to consultations with terminally-ill patient at the practice, 86% said their routine appointment time was 20 minutes or less and nearly half – 46% – were only able to offer 10 minutes or less. On average GPs spent longer on home visits but while a third – 33 – said they would ideally like to spend more than 40 minutes with patients, only 14% were able to. In response to the results of the survey, Marie Curie and the RCGP have called for a U.K.-wide Commission to make sure GPs and their practices have the time and resources to provide high quality end-of-life care. <https://goo.gl/j67yz8>

#### **Related**

- U.K. (England & Wales) | *The Guardian* – 1 November 2016 – ‘**Catholic church updates medieval “guide to dying well” for 21st century.**’ The Catholic church in England & Wales has brought the medieval manuscript *Ars Moriendi* – ‘The Art of Dying’ – into the digital age, with a website aimed at helping terminally ill people and their loved ones deal with death. Like the original 15th century work, ‘The Art of Dying Well’ is intended to bring religious comfort and offer practical guidance to people in the final stage of life. <https://goo.gl/bZsWhK>

#### **Report shows shortcomings in aged prison care**

AUSTRALIA (New South Wales) | SBS World News Radio (Sydney) – 2 November 2016 – A new report has found Australian prisons are failing to meet the needs of elderly prisoners. And the Salvation Army study – ‘Old behind bars: What is being done for the incarcerated?’ – has found elderly prisoners make up the fastest-growing prison population. At what age is a prisoner classified as aged? The latest research suggests it is just 50-years-old, or, for the Indigenous prison population, even younger, at just 45. Lead researcher Professor Bruce Stevens, of Charles Sturt University, says older prisoners are more vulnerable to poorer health outcomes in jail. The release of his research ... has renewed calls for a major overhaul in the country’s prison environment. <https://goo.gl/J35aRN>

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

#### **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- SOUTH AFRICA | Reuters – 4 November 2016 – ‘**South African appeal court starts “assisted dying” hearing.**’ South Africa’s Supreme Court of Appeal started hearing arguments in a case on assisted suicide ... after the government appealed against a ruling by a lower court granting a terminally ill patient the right to die... Assisted dying ... is illegal in South Africa. But in a groundbreaking ruling in 2015, South Africa’s High Court granted a terminally ill man, Robin Stransham-Ford, the right to die with dignity. Stransham-Ford died just hours before the High Court ruling was delivered. The government decided to appeal against the ruling, saying it had far-reaching implications on its interpretation and possible abuse by others in the absence of a legislative framework that regulates assisted suicide. <https://goo.gl/FEsr9c>

## Specialist Publications

### Population trends in New Zealand

#### **Am I too old for this, Doctor? Using population life expectancy to guide clinical decision-making**

*AUSTRALASIAN JOURNAL ON AGEING* | Online – 27 October 2016 – Prognostication is important in clinical decision-making, especially for older people. The aim was to present estimates of life expectancy for older people in New Zealand. Given current patterns and trends in New Zealand death rates, 50% of women reaching age 80 years in 2016 can expect to live at least another 10.5 years, 25% will live over 14.7 years, and 25% will die within 6.2 years. Comparable results for men reaching age 80 years in 2016 are 8.5 years, 12.7 years and 4.6 years, respectively. Of those reaching age 90 years in 2016, median expected years of life left is 4.2 years for women and 3.4 years for men. <https://goo.gl/x6S3l3>

#### **Helping palliative care healthcare professionals get the most out of mentoring in a low-income country: A qualitative study**

*BMC PALLIATIVE CARE* | Online – 3 November 2016 – The need to adequately support U.K.-based international health volunteers prior to, during and after their trip is recognised at government level. Whilst the need to support mentors is recognised little is known about their support needs. This study explores the lived experience of mentorship in a low-income country and gain insight into mentors' support and information needs and the barriers and facilitators to mentoring. Participants [in this study] became mentors to help others. Uncertainty about their achievements constituted a significant challenge. This study highlights the need to prepare mentors before their in-country visits by exploring motivation, describing the reality of international volunteering, and ensuring realistic expectations. Post-trip debriefing is important for reducing uncertainty around trip outcomes and maximising transferable impacts. Challenges to mentoring were logistical, related to the concept of mentorship and cultural. Facilitators included shared passion, mentor credibility and serendipity. Awareness of the support needs of mentors and the facilitators and challenges to mentoring can improve mentor preparation and support. This may minimise potential negative emotional impact of being a mentor, maximise positive personal and professional impacts and improve in-country project impact. <https://goo.gl/6leaHD>

#### **Addressing end-of-life care in cancer patients through “Ubuntu”: Lessons learned from Rwanda in global health perspective of humanity**

*CURRENT OBSTETRICS & GYNECOLOGY REPORTS* | Online – 29 October 2016 – Multi-disciplinary palliative care (PC) is rarely integrated into the public health care system at all levels in Africa. In Kigali, Rwanda, we have developed PC services for cancer patients and other incurable diseases, such as renal and heart failure, progressive neurologic diseases, and late stage HIV/AIDS for pediatric and adult patients in a district hospital and linked these services to home care. This article describes PC in Rwanda and to address end-of-life care issues in a post-genocide society. <https://goo.gl/dyx6tZ>



**N.B.** Ubuntu is a Nguni Bantu term loosely translating to “human kindness.”



### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.13.

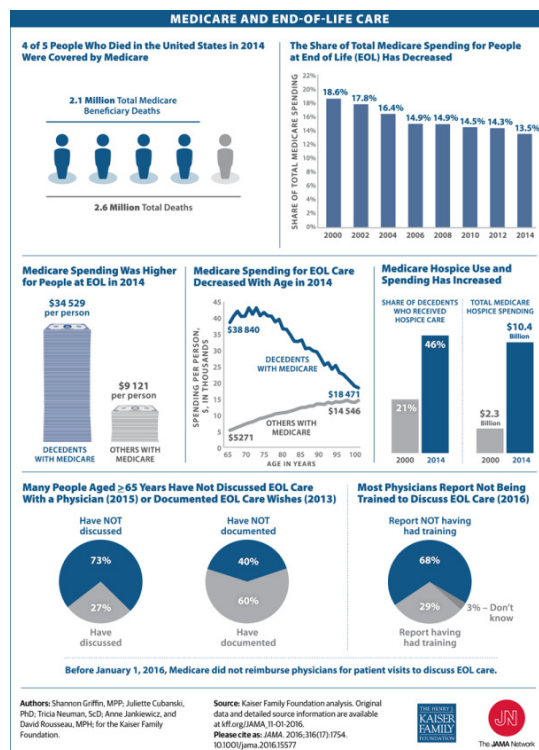
## Pain and social processes for hospice cancer patients: An integrative review

*EUROPEAN JOURNAL OF ONCOLOGY NURSING*, 2016;25(6):83-89. Hospice cancer patients experience poorly-controlled pain in spite of widely-disseminated evidence-based guidelines for use by hospice care practitioners. Pain management occurs in the context of the interdisciplinary team, centered on a caring triad in the home: the person with pain, their caregiver, and their nurse. This review: 1) Summarizes what is known about differing ways that members of the hospice caring triad (patients, caregivers, and nurses) interpret and respond to cancer pain, in order to develop a cancer pain social processes theoretical framework; 2) Identifies gaps in understanding of hospice cancer pain social processes; and 3) Identifies framework concepts for research-based clinical practice with potential to improve pain outcomes. This integrative review of the literature resulted in the identification and synthesis of 21 unique studies of cancer pain social processes, which were categorized according to a social processes framework and hospice caring triad member roles, using a social processes concepts matrix. Pain meanings, goals, and related responses vary for persons with pain, caregivers, and nurses. Studies have explored individual social processes concepts or triad member roles. Studies identify the need for pain meaning to be included in hospice pain management plans. To the authors' knowledge, no single study has generated a framework for hospice cancer pain social processes addressing and incorporating the roles of all three caring triad members. <https://goo.gl/cFHIWP>

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

#### Medicare and end-of-life care

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2016;316(17):1754. This Visualizing Health Policy infographic [right] provides a snapshot of Medicare and end-of-life (EOL) care. Of 2.6 million total deaths in the U.S. in 2014, 2.1 million were among Medicare beneficiaries. Although Medicare spent significantly more on care for people at the EOL who died in 2014 (\$34,529 per person) than for other beneficiaries that year (\$9,121 per person), the share of total Medicare spending for people at the EOL decreased from 18.6% to 13.5% between 2000 and 2014. Medicare spending for people at the EOL also decreased with age. Hospice use among Medicare beneficiaries at the EOL increased between 2000 and 2014 to nearly half (46%) of all beneficiaries. Medicare spending on hospice also increased during that period, from \$2.3 billion to \$10.4 billion. Surveys show that more than 7 in 10 people aged 65 years and older have not discussed EOL care with a physician and that 4 in 10 have not documented their EOL care wishes. Before 1 January 2016, Medicare did not reimburse physicians for patient visits to discuss EOL care, and as of 2016, 68% of physicians report that they have not received training for such discussions. <https://goo.gl/uGf5cy>



#### Related

- *AMA WIRE* (American Medical Association | Online – 1 November 2016 – ‘**Judgment on life expectancy at issue in Medicare fraud case.**’ A case before the U.S. Court of Appeals is threatening physicians’ ability to exercise their judgment. At stake in *U.S. of America v. GGNCS Administrative Services* is this question: When can a physician’s clinical judgment regarding a patient’s life expectancy – based on the normal course of a terminal illness – be considered false under the False Claims Act? In this case, the government alleges a hospice care center violated the False Claims Act by billing Medicare for services that did not qualify for reimbursement. <https://goo.gl/YrMjP5>

## State of research on palliative care in heart failure as evidenced by published literature, conference proceedings and National Institute of Health funding

*JOURNAL OF CARDIAC FAILURE* | Online – 28 October 2016 – Heart failure (HF) is the most common diagnosis in hospitalized patients over 65 years of age. Although these patients often need specialist-directed palliative care (PC), 10% ever receive these services. This may be due to a lack of evidence examining the benefits of PC for these patients. Of the journals reviewed, less than 1% of their publications related to PC. Less than 2% of HF-related sessions in conference proceedings mentioned PC. Of the National Institute of Health's (NIH) \$45 billion directed to HF research, only \$14 million (0.03%) was spent on PC research. Despite calls for improving PC for patients with advanced HF, a lack of sufficient attention persists in research abstracts, concurrent sessions at national meetings, and NIH funding to increase the evidence base. Without these improvements, the ability to deliver high quality specialist PC to patients with HF and their families will remain severely limited. <https://goo.gl/xLzkOb>

Noted in Media Watch 11 April 2016, #457 (p.9):

- *JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2016;67(13S):1553-1553. '**Mind the gap: Palliative care knowledge among cardiovascular clinicians.**' In this survey, College members who care for patients with transcatheter aortic valve replacements and ventricular assist devices acquired palliative care (PC) knowledge through practical experience and/or independent learning, not training program didactics. Nonetheless, over half expressed interest in dedicated PC education. These results highlight an unmet need in cardiovascular training and provide a call for more structured PC-focused educational opportunities. <http://goo.gl/zQZVmJ>

**N.B.** Additional articles on palliative care and cardiology noted in Media Watch 15 August 2016, #475 (p.5), 11 January 2016, #444 (pp.9-10), and 19 January 2015, #393 (pp.11-12).

## Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline updated

*JOURNAL OF CLINICAL ONCOLOGY* | Online – 31 October 2016 – The updated guideline reflects changes in evidence since the previous guideline. Nine randomized controlled trials (RCTs), one quasi-experimental trial and five secondary analyses from RCTs in the 2012 provisional clinical opinion on providing palliative care (PC) services to patients with cancer and/or their caregivers, including family caregivers, were found to inform the update. It is recommended that inpatients and outpatients with advanced cancer should receive dedicated PC services early in the disease course, concurrent with active treatment. Referral of patients to interdisciplinary PC teams is optimal, and services may complement existing programs. Providers may refer family and friend caregivers of patients with early or advanced cancer to PC services. <https://goo.gl/zaRNuP>

### Related

- *JOURNAL OF CONTINUING EDUCATION IN NURSING*, 2016;47(11):487-489. '**A critical "P" in patient-centered care: Palliative care for all of us.**' Palliative care, an important interdisciplinary care modality, is not just for the terminally ill. The Institute of Medicine calls the improvement of end-of-life care a national priority.<sup>1</sup> Developing a culture of ongoing integration of topics such as palliative care into a patient-focused care curriculum would be a lasting and important contribution from professional development educators. <https://goo.gl/PsDSor>

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://goo.gl/6Q5VNY>



## **Social determinants, multi-morbidity, and patterns of end-of-life care in older adults dying from cancer**

*JOURNAL OF GERIATRIC ONCOLOGY* | Online – 28 October 2016 – Most prior studies on aggressive end-of-life care (EOLC) in older patients with cancer have accounted for social determinants of health (e.g., race, income, and education), but rarely for multi-morbidity (MM). The authors examine the association between EOLC and each of the social determinants of health and MM, hypothesizing that higher MM is associated with less aggressive care. In this study, while 61.2% of the patients enrolled in hospice, 24.6% underwent cancer-directed treatment; 55.1% were admitted to the hospital and/or ED; and, 21.7% died in the hospital. The authors observed a U-shaped distribution between income and in-hospital death. Chronic conditions and geriatric syndromes were associated with some outcomes, but not with others. To improve quality EOLC and curtail costs incurred by dying patients, relevant interventions need to account for social determinants of health and MM in a nuanced fashion. <https://goo.gl/y1autJ>

## **Care for dying patients at midlife: Experiences of nurses in specialized palliative home care**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(6):564-571. Three themes and 9 codes represented the [study] participants' experiences and coping strategies: 1) Experiences of significances: participants felt admiration for the patients, they became invigorated by their encounters with their patients, and they got confirmation that they did well; 2) Stress: participants described how they were affected by external influences, psychological stress, and stress-related symptoms; and, 3) Coping: participants described the various individual-, group-, and organizational-level coping strategies they used in their daily work and the formal and informal support they received. Based on their descriptions, palliative care nursing was stressful for the nurses. They had various coping strategies and significances that helped them care for the families in the most difficult situations. <https://goo.gl/fnxfJO>

## **Caring for dying patients in the nursing home: Voices from frontline nursing home staff**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 November 2016 – Little is known about the perspectives of the front line staff who provide a majority of ... [nursing homes] ... care. Respondents were largely female (93%), white (78%), 31-50 years (42%), and 53% had 5 years of work experience. Experiences were described from three perspectives: 1) First-hand experiences; 2) Observed experiences of dying patients; and, 3) Observed experiences of family members. Selected themes for positive experiences include: creating close bonds; good patient care; involvement of hospice; being prepared; and, good communication. Selected themes for negative experiences consisted of: challenging aspects of care; unacknowledged death; feeling helpless; uncertainty; absent family; painful emotions; and, family discord. Findings reveal the richness and many complexities of providing end-of-life care in nursing homes, and have implications for improving staff knowledge, coordination of care with hospice, and social support for patients. <https://goo.gl/UwwBM4>

Noted in Media Watch 31 October 2016, #485 (p.7):

- *NORDIC JOURNAL OF NURSING RESEARCH* | Online – 21 October 2016 – '**Preserving dignity in end-of-life nursing home care: Some ethical challenges.**' The authors' findings indicate that nursing homes do not provide necessary organizational frames for the team approach that characterizes good palliation, and therefore struggle to give dignified care. Ethical challenges experienced by health-care workers are closely connected to inadequate organizational frames. <https://goo.gl/qquHPu>

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

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):222-226. '**Improving end-of-life care in nursing homes: An innovative model of education and training.**' In England, a team from the Royal Marsden National Health Service Foundation Trust in London have set up an innovative model of training to help nursing home staff, as well as local GPs, improve end-of-life care for nursing home residents. The model has been rolled out in 33 nursing homes... It encompasses education and training, clinical rounds, advice and guidance, communication, and care co-ordination.

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

## How Islam influences end-of-life care: Education for palliative care clinicians

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 October 2016 – Palliative care clinicians should have at least a basic understanding of major world religions. Islam is a major world religion with 1.7 billion followers. At the author's institution, a needs assessment showed a lack of knowledge with Islamic teachings regarding end-of-life care (EOLC). In a pilot study, a one-hour educational intervention improved knowledge of Islamic teachings regarding EOLC. The authors present a framework for this intervention, which can be easily replicated. They also provide key teaching points on Islam and EOLC. Additional research is necessary to determine the clinical effects of this intervention over time and in practice. <https://goo.gl/LpbVlq>

Noted in Media Watch 12 September 2016, #479 (p.11):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 9 September 2016 – ‘**Islamic perspectives on clinical intervention near the end-of-life: We can but must we?**’ This paper argues that traditional Sunni Islamic ethico-legal views on the obligation to seek medical care and Islamic theological concepts of human dignity (karāmah) and inviolability (ḥurmah) provide the ethical grounds for non-intervention at the end of life and can help calibrate goals of care discussions for Muslim patients. <http://goo.gl/ybZEgi>

Noted in Media Watch 1 February 2016, #447 (p.14):

- *CLINICAL JOURNAL OF ONCOLOGY NURSING*, 2016;20(1):11-12. ‘**Providing culturally appropriate care to American Muslims with cancer.**’ The population of Muslims in the U.S. is projected to dramatically increase in the next few decades. Understanding the role of Islam for people who believe in and follow Islam will provide nurses with important perspectives that affect health behaviors, cancer screening, treatment decision-making, and end-of-life care. <https://goo.gl/OxOV04>

**N.B.** Additional articles on Islam and end-of-life care are noted in Media Watch 1 February 2016, #447 (p.13).

## The quality of Physician Orders for Life-Sustaining Treatment (POLST) decisions: A pilot study

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 November 2016 – A majority (59%) of participants recognized the POLST form. Participants were generally accurate in their knowledge of how POLST orders guide treatment concerning cardiopulmonary resuscitation (CPR) (68%), antibiotics (74%), and artificial nutrition (79%), but less so for medical interventions (50%). Current treatment preferences were initially discordant with one or more POLST orders for 64% (18/28) of participants, but half of these discordances were resolved with further discussion (e.g., participant agreed with the existing order). Discordance by treatment decision was as follows: CPR (7%), level of medical intervention (18%), antibiotics (21%), and artificial nutrition (11%). Discordance between current preferences and POLST orders is complex. Interventions are needed to support high-quality POLST decisions that are informed and concordant with current preferences. <https://goo.gl/YNhUfU>

### Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 November 2016 – ‘**Racial differences in associations of perceived health and social and physical activities with advance care planning, end-of-life concerns, and hospice knowledge.**’ Results [of this study] showed that black older adults were less likely to know about or document advance care planning and to have accurate knowledge of hospice care; however, despite their poorer perceived health, black older adults reported fewer end-of-life (EOL) concerns. Both black and white older adults with poorer perceived health and lower levels of social and physical activities tended to have more EOL concerns and less knowledge of hospice care. <https://goo.gl/Rn5q3w>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 November 2016 – ‘**Experiences and perspectives on advance care planning among individuals living with serious physical disabilities.**’ Despite frequent encounters with the healthcare system and high risk for secondary conditions, it is unclear how frequently individuals living with serious physical disabilities document advance directives (AD) or engage in advance care planning (ACP). Their perspectives on these topics are largely unknown. Five organizing themes emerged in this study: 1) AD is a right versus responsibility; 2) Past medical experiences influence ACP engagement; 3) ACP requires relationship-centered decision support; 4) Concerns for care after death; and, 5) Suggestions for improving ACP experiences. <https://goo.gl/gvjGWI>

### **Taking the spell off of death: Media as mourning ritual in Russia’s psychic challenge**

*LABORATORIUM: RUSSIAN REVIEW OF SOCIAL RESEARCH*, 2016;2:33-39. Modern Russian society can be seen as practicing both traditional and modern types of ritual mourning. On the one hand, it is not a traditional community with a shared structure of religious practices. On the other hand, a complex infrastructure of social and psychological support to bereaved people is not available yet. In such circumstances, the functions of mourning rituals – to work out fear of death, rebuild communities, and so forth – are delegated to other agents of discourse. <https://goo.gl/BoC58h>

**N.B.** Link is to both the Russian and English language versions of the journal article.

### **Factors associated with patient preferences for communication of bad news**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 2 November 2016 – This study aimed to explore the demographic, medical, and psychological factors associated with patient preferences with regard to communication of bad news. Outpatients with a variety of cancers were consecutively invited to participate ... after their follow-up medical visit. A questionnaire assessed their preferences regarding the communication of bad news, covering four factors: 1) How bad news is delivered; 2) Reassurance and emotional support; 3) Additional information; and, 4) setting – as well as on demographic, medical, and psychosocial factors. Multiple regression analyses indicated that patients who were younger, female, had greater faith in their physician, and were more highly educated placed more importance on “how bad news is delivered” than patients who were older, male, had less faith in their physician, and a lower level of education. Female patients and patients without an occupation placed more importance on “reassurance and emotional support.” Younger, female, and more highly educated patients placed more importance on “additional information.” Younger, female, and more highly educated patients, along with patients who weren’t undergoing active treatment placed more importance on “setting.” Physicians should consider these characteristics when delivering bad news and use an appropriate communication style tailored to each patient. <https://goo.gl/Rd4CjX>

Noted in Media Watch 4 July 2016, #469 (p.3):

- U.S. | *The New York Times* – 1 July 2016 – ‘**What doctors know about how bad it is, and won’t say.**’ Experts have repeatedly urged doctors to talk about the elephants in the room, especially at the end of life. But two recent studies show how achingly slow progress has been.<sup>1,2</sup> Even terminally ill patients still receive scant information, researchers have found, while family members acting for ICU patients commonly contend with confusion and misinformation. The studies uncover some reasons for the disconnect. Doctors, it seems, shouldn’t get all the blame. <http://goo.gl/sXnslm>
  1. ‘Discussions of life expectancy and changes in illness understanding in patients with advanced cancer,’ *Journal of Clinical Oncology*, 23 May 2016. <http://goo.gl/K2szxn> [Noted in Media Watch, 30 May 2016, #464 (p.3)]
  2. ‘Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients,’ *Journal of the American Medical Association*, 2016;315(19): 2086-2094. [Noted in Media Watch, 2016, #463 (p.4)] <http://goo.gl/VG6Xf3>

## Support for using five attributes to describe spirituality among families with a parent in hospice

*PALLIATIVE & SUPPORTIVE CARE* | Online – 2 November 2016 – The present research supports the use of a spiritual framework consisting of five common attributes (meaning, beliefs, connections, self-transcendence, and value) as a mechanism for viewing spirituality for people nearing the end of life. This study aims to describe the prevalence of spirituality and its nature according to these five spiritual attributes. Data from two previous studies were analyzed. The first employed the methods of grounded theory to understand the strategies adolescents used to manage the impending death of a parent. Some 61 participants from 26 families were interviewed, including ill parents/patients, well parents/caregivers, and adolescents. The second study consisted of 15 interviews with the surviving parent and adolescents from 6 of these families after the death of the parent. The original research from which these data were drawn did not seek to describe spirituality. However, spiritual themes were prevalent in the stories of many participants and included each of the five spiritual attributes. The authors findings demonstrate the prevalence of spirituality in the everyday lives of these families and supports the use of the spiritual framework according to the five common attributes to describe spirituality. <https://goo.gl/XItULx>

**N.B.** Additional articles on “spiritual care” in the context of end-of-life care noted in Media Watch 24 October 2016, #484 (p.12) and 12 September 2016, #479 (p.12).

## Anticipatory prescribing for end-of-life care: A survey of community nurses in England

*PRIMARY HEALTH CARE* | Online – 27 October 2016 – Anticipatory prescribing is increasingly common in the U.K., yet little is known about nurses’ roles in the process. As part of a wider study, a postal survey of 575 community or district, nursing home and palliative care nurses was undertaken in two regions. Responses appeared to show anticipatory prescribing as a common practice and, once in place, prescriptions were often used. Nurses reported taking prominent roles throughout the anticipatory prescribing process and principal responsibility for administering and monitoring medications. Many respondents recounted good working relationships with GPs. However, some reported issues including being challenged by GPs who were reluctant to prescribe medication, being given incorrect prescriptions and having difficulty in gaining access to the necessary medications. Qualitative comments indicated that being a nurse prescriber could enhance confidence to use anticipatory prescriptions. Importantly, respondents perceived that anticipatory prescriptions facilitated provision of good end-of-life care. <https://goo.gl/D5b0N3>

Noted in Media Watch 17 October 2016, #483 (p.16):

- *PRESCRIBER* | Online – Accessed 14 October 2016 – ‘**Anticipatory prescribing for end-of-life care.**’ In patients receiving end-of-life care at home, anticipatory prescribing can provide a back-up for when urgent symptom control is needed. This article discusses the practicalities surrounding anticipatory prescribing, including the use of “just in case” boxes, the role of family members, and how to handle difficult conversations with patients. <https://goo.gl/LDWcbM>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 26 October 2016 – “**We need to talk!**” **Barriers to GPs’ communication about the option of physician-assisted suicide and their ethical implications: Results from a qualitative study.**’ GPs usually care for their patients for an extended period of time, therefore, requests to not only discontinue a patient’s treatment, but to assist a patient in a suicide are likely to create intensely stressful situations for physicians. However, in order to ensure the best patient care possible, the competent communication about the option of physician assisted suicide (PAS) as well as the assessment of the origin and sincerity of the request are very important. This is especially true, since patients’ requests for PAS can also be an indicator for unmet needs or concerns. The analysis of the gathered data shows three main themes why GPs may find it difficult to professionally communicate about PAS: concerns for their own psychological well-being, conflicting personal values or their understanding of their professional role. <https://goo.gl/1KduLx>

Cont.

Noted in Media Watch 24 October 2016, #484 (p.13):

- *PALLIATIVE MEDICINE* | Online – 19 October 2016 – ‘**Assessment of the wish to hasten death in patients with advanced disease: A systematic review of measurement instruments.**’ Of the seven instruments identified, the Desire for Death Rating Scale or the Schedule of Attitudes toward Hastened Death feature in 48 of the 50 articles. The Schedule of Attitudes toward Hastened Death is the most widely used and is the instrument whose psychometric properties have been most often analysed. Versions of the Schedule of Attitudes toward Hastened Death are available in five languages other than the original English. <https://goo.gl/tgJmM4>

**N.B.** Additional articles on the desire to hastened death noted in Media Watch 7 March 2016, #452 (pp.8-9)

- *SOUTH AFRICAN JOURNAL OF PSYCHIATRY* | Online – 24 October 2016 – ‘**Developing the language of futility in psychiatry with care.**’ In the discipline of psychiatry, physician-assisted suicide may be an option, but warrants careful consideration. Contemporary psychiatrists may act paternalistically, refusing to accept the limitations of their scientific skills and/or struggle with the moral good of “letting go” when required. It is arguably the seeming complexity of gauging patients’ understanding (competency, capacity) to make informed decisions that perpetuates futile treatment. Most patients, even in the presence of ongoing serious psychiatric illness, are able to give consent. Psychiatrists should be aware of the difference between being alive and living. Ongoing suffering cannot be condoned. The personhood of every patient and his/her bio-psycho-social and spiritual needs should, as far as possible, be respected. Psychiatrists should embrace the realisation of treatment futility and, in some cases, end-of-life decisions and take on the challenge as well as the responsibility of serving patients with mental illness in the best way possible. <https://goo.gl/uTGMkg>

### [Media Watch: Online](#)

#### **International**

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

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

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

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

#### **Asia**

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

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

#### **Canada**

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

#### **Europe**

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

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

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



### Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.  
<http://goo.gl/OTpc8l>

### Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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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.

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