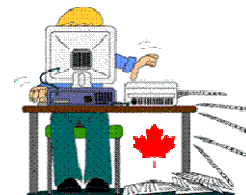


## Media Watch...

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.

15 May 2017 Edition | Issue #512



Compilation of Media Watch 2008-2017 ©

Compiled & Annotated by Barry R. Ashpole

**End-of-life care in non-cancer diseases: Scroll down to [Specialist Publications](#) and 'Palliative care in heart failure: What triggers specialist consultation? (p.11), in *Progress in Cardiovascular Diseases*.**

## [Canada](#)

### Access to high-quality palliative care needs to be a priority in Canada

CONFERENCE BOARD OF CANADA | Online – 10 May 2017 – A new report summarizes the pan-Canadian consensus statement published by Palliative Care Matters in 2016 – which offered recommendations on how Canada can improve access to palliative care (PC) – and goes on to outline steps to move from recommendations to action.<sup>1,2</sup> 1) Canada needs to develop enhanced palliative and end-of-life care (P&EoLC) capacity in home, community, and long-term care settings; 2) The future demand for P&EoLC services means governments and other stakeholders must develop workforce capacity; 3) As caregivers are the main providers of PC in homes and communities, their input is essential; 4) P&EoLC is changing – perhaps more than previously known – and more evidence and insights into the palliative and end-of-life needs and expectations of Canadians are needed; and, 5) While examples of high-quality hospice and innovative PC programs can be found across Canada, many were developed organically through local leadership and resources, and access is uneven within and across jurisdictions, with some populations significantly underserved. <https://goo.gl/vZYbxv>

1. 'Palliative Care Matters: How Canada's Health System Needs to Change,' Consensus Statement, November 2016. [Noted in Media Watch 14 November 2016, #487 (p.1)] <https://goo.gl/PFvxpM>
2. 'Palliative Care Matters: Fostering Change in Canadian Health Care,' Conference Board of Canada, May 2017. <https://goo.gl/nClilZ>

**N.B.** See 'Access to palliative care in Canada,' an overview of past studies in the 25 April 2016 issue of Media Watch 25 (#459, p.1)



### 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.15.

## Montreal's Maison du Père to offer palliative care to its homeless clients

QUEBEC | *The Montreal Gazette* – 10 May 2017 – The Maison du Père has been helping the homeless of Montreal for the past 48 years. Now the shelter on René-Lévesque Boulevard East is going to offer palliative care (PC) service to its clients so they can live out their final days in a dignified and caring manner. François Boissy, general manager of Maison du Père, announced a new partnership with the Palliative Home Care Society of Greater Montreal that would enable the shelter to offer two PC units and two life-ending care rooms for homeless men. On aver-

age, about 30 men who use Maison du Père programs pass away each year, Boissy said. <https://goo.gl/GSLBbx>

### Specialist Publications

**'Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice'** (p.12), in *Pubic Health Nursing*.

## Care of aging parents costs Canadians an estimated \$33 billion annually

CBC NEWS | Online – 8 May 2017 – Caring for aging parents costs Canadians an estimated \$33 billion a year in out-of-pocket expenses and time taken from work, and that figure is expected to grow, according to a report by economists at CIBC [the Canadian Imperial Bank of Commerce]. “An aging population, combined with longer life spans and strained social services, has in recent years seen more and more Canadians taking on the role of caregiver for their aging parents,” CIBC deputy chief economist Benjamin Tal and senior economist Royce Mendes said in their report [‘Who Cares: The Economics of Caring For Aging Parents’]. That tendency is likely to intensify in the coming years, they add. The latest census data indicates seniors now outnumber children in Canada, as the population has experienced its greatest increase in the proportion of older people since Confederation [in 1867].<sup>1</sup> According to CIBC, the proportion of Canadians aged 65 and over sits at 17% of the population, but that figure is expected to rise to 22% in 10 years. <https://goo.gl/xP4TDq>

1. ‘Age and Sex, and Type of Dwelling Data: Key results from the 2016 Census,’ Statistics Canada, May 2017. [Noted in Media Watch 8 May 2017, #511 (p.1)] <https://goo.gl/5O0agb>

### Selected articles on family caregivers in the context of elder care

- *THE OTTAWA CITIZEN* | Online – 29 July 2016 – **“Army of unpaid caregivers” should be compensated for senior care: Survey.** Family and friends should get financial compensation for the hours they put into senior care.<sup>1</sup> More than three million Canadians dedicated 1.5 billion hours of home support and community care in 2007, offering 10 unpaid hours of care for every paid hour. [Noted in Media Watch 8 August 2016, #474 (p.2)] [goo.gl/hDr6VP](http://goo.gl/hDr6VP)
  1. ‘Feeling at Home: A Survey of Canadians on Senior Care,’ The Conference Board of Canada, 28 July 2016. <http://goo.gl/yil78l>
- ONTARIO | *The Toronto Star* – 5 April 2016 – **‘Caregivers are needed more than ever, but burning out.’** Distress among unpaid caregivers who bear the heavy burden of looking after ill, elderly or disabled relatives has doubled in four years, according to the provincial government’s adviser on quality of health care.<sup>1</sup> [Noted in Media Watch 11 April 2016, #457 (p.2)] <http://goo.gl/XXwdwe>
  1. ‘The Reality of Caring: Distress Among the Caregivers of Home Care Patients,’ Health Quality Ontario, April 2016. <http://goo.gl/xkSYRP>
- *THE GLOBE & MAIL* | Online – 2 October 2014 – **‘Why Canada’s reliance on unpaid care is not sustainable.’** More than two million individuals received homecare in 2012.<sup>1</sup> Most consider that over a one-year period they received all the services they required to help with their daily activities. Only a minority said they had unmet homecare needs. [Noted in Media Watch 6 October 2014, #378 (p.3)] <http://goo.gl/qWHeDZ>
  1. ‘Canadians with Unmet Home Care Needs,’ Statistics Canada, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.3)] <http://goo.gl/oBNrck>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | Ministry of Health & Long Term Care – 9 May 2017 – **‘Ontario passes legislation on medical assistance in dying.’** Ontario’s Medical Assistance in Dying Statute Law Amendment Act aligns with federal legislation and addresses areas that fall under provincial jurisdiction: 1) Benefits, such as insurance payments and workplace safety, and insurance benefits, are not denied only because of a medically assisted death; 2) Physicians and nurse practitioners, those who assist them, and care provider institutions, are protected from civil liability when lawfully providing medical assistance in dying, except in cases of negligence; 3) Identifiable information about individuals and facilities that provide medical assistance in dying are protected from disclosure under access to information requests; and, 3) Effective ongoing reporting and monitoring by the Chief Coroner of Ontario for cases of medical assistance in dying. <https://goo.gl/qlux4l>

## U.S.A.

### We’re bad at death. First, we need a good talk

*THE NEW YORK TIMES* | Online – 10 May 2017 – For years the medical profession has largely fumbled the question of what we should do when there’s nothing more we can do. A new wave of research sheds light on what patients want at the end of life (EoL), and who is – or isn’t – getting it. Despite growing recognition that more care isn’t necessarily better care, particularly at the EoL, many Americans still receive an enormous dose of medicine in their final days. On average, patients make 29 visits to the doctor’s office in their last six months. In their last month alone, half of Medicare patients go to an emergency department, one-third are admitted to an ICU, and one-fifth will have surgery – even though 80% of patients say they hope to avoid hospitalization and intensive care at the EoL. Medicare spending for patients in the last year of life is six times what it is for other patients, and accounts for a quarter of the total Medicare budget – a proportion that has remained essentially unchanged for the past three decades. It’s not clear all that care improves how long or how well people live. Patients receiving aggressive medical care at the EoL don’t seem to live any longer, and some work suggests a less aggressive approach buys more time. Despite a popular misconception, doctors don’t die much differently. <https://goo.gl/iPsgqj>

### Specialist Publications

**‘A moving target: Medicare beneficiaries coming to the end of long lives’** (p.8), in *Journal of the American Geriatric Society*.

**‘Building bridges between civil rights movements of people with disabilities and those with terminal illness’** (p.14), in *University of Pittsburgh Law Review*.

### Related

- MASSACHUSETTS | *The Boston Globe* – 9 May 2017 – **‘Medical schools to teach how to discuss patients’ goals-for-care – and for life.’** The four medical schools in Massachusetts have jointly agreed to teach students and residents how to talk with patients about what they want from life, so future doctors will know how far to go in keeping gravely ill patients alive. How patients answer questions about their overall life goals can inform treatment decisions, especially as people near the end of life. <https://goo.gl/03mtSU>

## **From primary care to hospice: Treating aging inmates and ex-offenders**

CONNECTICUT | National Public Radio (Hartford) – 8 May 2017 – Connecticut’s prison population is getting older, upping the demand for healthcare, including hospice programs that serve inmates and ex-offenders. [In this episode of ‘Where We Live’], we find out what it means to die with dignity behind bars. We hear about a hospice program for prisoners at Osborn Correctional Institution in Somers, Connecticut, and the younger inmates who care for the dying. We look to Louisiana to find out how that state cares for its aging population. And we hear about a nursing home in Rocky Hill, Connecticut, that is getting attention beyond state lines. But first, we learn about why a Medicaid program designed to help aging ex-offenders in their communities hangs in the balance in Washington. What do you think should be the role of the state and federal government in caring for aging offenders? <https://goo.gl/tDqf5e>

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

## **Life expectancy can vary by 20 years depending on where you live**

NATIONAL PUBLIC RADIO | Online – 8 May 2017 – There’s more grim news about inequality in America. New research documents significant disparities in the life spans (LS) of Americans depending on where they live. And those gaps appear to be widening... “It’s dramatic,” says Christopher Murray, who heads the Institute for Health Metrics & Evaluation at the University of Washington. He helped conduct the analysis...<sup>1</sup> Health experts have long known that Americans living in different parts of the country tend to have different LS. But Murray’s team decided to take a closer look, analyzing records from every U.S. county between 1980 and 2014. “What we found is that the gap is enormous,” Murray says. In 2014, there was a spread of 20.1 years between the counties with the longest and shortest typical LS based on life expectancy at birth. In counties with the longest LS, people tended to live about 87 years, while people in places with the shortest LS typically made it to only about 67, the researchers found. The discrepancy is equivalent to the difference between the low-income parts of the developing world and countries with high incomes. <https://goo.gl/Hja98U>

1. ‘Inequalities in life expectancy among U.S. counties: Temporal trends and key drivers 2014-1980,’ *JAMA Internal Medicine*, published online 8 May 2017. <https://goo.gl/8mRNFz>

## **International**

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

#### **Most people would be willing to give injections to improve quality of life for a dying person**

U.K. | Dying Matters – 8 May 2017 – In a poll, 39% of British adults say they would feel comfortable giving a pain-relief injection to someone who was dying and wanted to stay home, after receiving some training and with no additional support. This rises to 61% with doctor or nurse supervision the first few times. Lack of access to pain and symptom relief around the clock can both result in emergency admissions and prevent people from being able to leave hospital, instead of being at home when they die. The survey also found people both disagreeing that dying is only a matter for professional health and social care services (70%) and agreeing that they would be willing to offer practical help and support other people who are dying (74%) – as well as saying they would expect their friends and neighbours to support them if they were caring for a relative dying at home (61%). Only 16% agreed that there is currently enough support for people dealing with death dying and bereavement, with 55% disagreeing. <https://goo.gl/oXxqVG>

Cont.

## Selected articles related to family caregivers administering medications in the context of end-of-life care

- U.K. (England) | National Institute for Health & Care Excellence (NICE) – 17 October 2016 – **‘Home care services should give people more responsibility to manage their medicines, says National Institute for Health & Care Excellence.’** In a new draft guideline being published for public consultation, the Institute has set out how staff can help adults who are receiving social care support at home to manage their medicines safely and correctly. [Noted in Media Watch 24 October 2016, #484 (p.4)] <https://goo.gl/sLzAyK>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 March 2016 – **‘Family caregivers’ pain management in end-of-life care: A systematic review.’** This review identified themes similar to previous reviews on family caregivers of patients with cancer or in palliative care: inadequate knowledge and assessment skills in pain management, misunderstanding of pain medications, and poor communication with the care team. [Noted in Media Watch 21 March 2016, #454 (p.7)] <http://goo.gl/iE15nG>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 September 2014 – **‘Managing end-of-life medications at home: Accounts of bereaved family carers.’** Although some support with medications is provided by GPs and nurses in the community, family carers take primary responsibility for drug administration and storage. They report anxiety about giving correct and timely dosages and concerns about keeping the patient comfortable without overdosing them or risking shortening their lives. [Noted in Media Watch 29 September 2014, #377 (p.9)] <http://goo.gl/bHWZCx>

## Specialist Publications

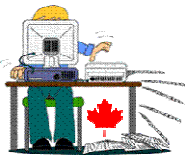
‘Decision-making on withholding or withdrawing life-support in the ICU: A worldwide perspective’ (p.7), in *Chest*.

‘The development of palliative care in Argentina: A mapping study using Latin American Association for Palliative Care indicators’ (p.8), in *Journal of Palliative Medicine*.

‘Randomised clinical trial of early specialist palliative care plus standard care versus standard care alone in patients with advanced cancer: The Danish Palliative Care Trial’ (p.11), in *Palliative Medicine*.

‘Chronic illness needing palliative care in Kinshasa hospitals, Democratic Republic of the Congo’ (p.13), in *Tropical Medicine & Health*.

‘Suicide and assisted dying in dementia. What we know and what we need to know. A narrative literature review’ (p.14), in *International Psychogeriatrics*.



## Barry R. Ashpole

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

## Specialist Publications

### **Managing bias in palliative care: Professional hazards in goals-of-care discussions at the end of life**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 10 May 2017 – In the setting of end-of-life (EoL) care, biases can interfere with patient articulation of goals and hinder provision of patient-centered care. No studies have addressed clinician bias or bias management specific to goals-of-care discussions at the EoL. The twenty clinicians interviewed identified 16 biases and 11 bias management strategies. The most frequently mentioned bias was a bias against aggressive treatment, described as a clinician's assumption that most interventions at the EoL are not beneficial. The most frequently mentioned bias management strategy was self-recognition of bias... <https://goo.gl/l13ygR>

### **Death and dignity: Exploring physicians' responsibilities after a patient's death**

*AMERICAN JOURNAL OF MEDICINE* | Online – 11 May 2017 – Literature focused on care at the end of life (EoL) is flourishing. The scope of this work has been broad, including how to best communicate bad news or discuss patient wishes at the EoL, as well as detailing where patients are dying and how it impacts their care, and the value of palliative and hospice care during this process. As literature on EoL care grows, more attention is also being paid to the importance of caring for bereaved family members, highlighting the need to continue to care for those left behind. <https://goo.gl/FFT5U6>

#### **Related**

- *DEATH STUDIES* | Online – 11 May 2017 – '**What determines supportive behaviours following bereavement? A systematic review and call to action.**' Very few factors that impact the grieving process can be modified after the fact to the extent that social support can. However, social support has received limited research attention, resulting in little conceptual understanding of the mechanisms behind perceptions of, and intentions to support, grieving persons. <https://goo.gl/KksID7>

### **Rethinking priorities: Experience of an educational initiative to change attitudes, behaviours and clinical practice in end-of-life care**

*BMJ SUPPORTIVE CARE & PALLIATIVE CARE* | Online – 8 May 2017 – To implement the National End-of-Life Care Strategy and enable more people to express and achieve their preferences about care at the end of life (EoL), senior clinicians outside palliative medicine need to make it a routine part of their practice. However, it is acknowledged that recognising that people are entering the last phase of their illness is not always straightforward, and having conversations about aims of treatment and planning for future care may not be easy. This [pilot] programme involved individual clinicians identifying their own learning needs and specific issues for EoL care in their patients. The authors describe the programme and its outcomes, especially in relation to participants' learning, service development, and leadership. It also highlights the challenges, including different learning styles, the concept of action learning, obtaining funding and dedicated time, and how to evaluate the effectiveness of the programme. Overall, it suggests an educational initiative based on clini-

ans identifying their own learning needs, and using an action learning approach to explore issues with other colleagues, with the addition of some targeted sessions, can result in positive change in knowledge, behaviour, and clinical practice. <https://goo.gl/XCSnbe>

#### **Disseminating effective clinician communication techniques: Engaging clinicians to want to learn how to engage patients**

*PATIENT EDUCATION & COUNSELING* | Online – 9 May 2017 – In this paper, the authors argue that both top-down approaches (mandated by institutions) should be coupled with bottom-up approaches that address clinician motivation, confidence, and barriers. There is a need to engage clinicians in the same way we ask them to engage patients – strategically and with empathy. The authors discuss potentially innovative strategies to integrate top-down and bottom-up approaches in ways that fit clinicians' busy schedules and can inform policy. <https://goo.gl/4HLVM5>

## Decision-making on withholding or withdrawing life-support in the ICU: A worldwide perspective

*CHEST* | Online – 5 May 2017 – The authors documented the characteristics of intensive care unit (ICU) patients with a decision to withhold/withdraw life-sustaining treatment, including the types of supportive treatments used, patterns of organ dysfunction, and international differences... The study was conducted in 730 ICUs in 84 countries. The analysis included 9,524 patients, with a hospital mortality of 24%. A decision to withhold/withdraw life-sustaining treatment was reported during the ICU stay in 1,259 patients (13%), including 820 (40%) non-survivors and 439 (5%) survivors. Hospital mortality in patients with a decision to withhold/withdraw life-sustaining treatment was 69%. There is considerable worldwide variability in decisions to withhold/withdraw life-sustaining treatments [10% in South Asia to 67% in Oceania]. Interestingly, almost one-third of patients with a decision to withhold/withdraw life-sustaining treatment left the hospital alive. <https://goo.gl/CtjSVD>

## Palliative care in cardiac transplantation: An evolving model

*HEART FAILURE REVIEWS* | Online – 5 May 2017 – It is currently estimated that 5.7 million Americans live with heart failure. Of these, less than 3,000 will receive a heart transplant this year, according to the U.S. Department of Health & Human Services' Organ Procurement & Transplantation Network. Although palliative care (PC) is an interdisciplinary sub-specialty designed to alleviate multiple domains of suffering in serious illness, many mistakenly associate it solely with the end of life. Traditionally associated with cancer, research into the role of PC in other chronic illnesses and complex life-changing therapies such as solid organ transplantation remains scarce, but is nonetheless developing. The authors investigate a potential role for PC for heart transplant recipients. Early research thus far has demonstrated importance of early involvement of PC teams and the significant improvement of physical and emotional symptoms in the pre- and post-transplant period. Nevertheless, more research is warranted to determine the ideal timing of PC integration, the effects on health care resource utilization, and whether improving quality of life can affect morbidity and mortality. By understanding these critical elements and others we may be able to develop a model for the role of PC for heart transplant patients. <https://goo.gl/Bd2ggj>

**N.B.** Additional articles on organ transplantation in the context of palliative care are noted in the 14 November 2016 issue of Media Watch.

## Surrogate prediction of quality-of-life and desire for treatment: A guess of a guess

*INTERNATIONAL PSYCHOGERIATRICS* | Online – 5 May 2017 – In conditions, such as dementia, stroke, or critical illness, clinicians often rely on substituted judgment through a surrogate to assist in medical decision making. Surrogates may face tough decisions regarding whether to pursue or forego surgery, tube feeding, and cardiopulmonary resuscitation. Surrogates often have little confidence in their decision, though substituted judgment relies on the surrogate to determine the decision that the patient would have made. Prior studies suggest that surrogates predict patient preferences with only 68% accuracy. Bravo and colleagues explores differences in quality-of-life assessments between patients and surrogates as a potential explanation for surrogate inaccuracy.<sup>1</sup> <https://goo.gl/wbQV4Z>

1. 'Surrogate inaccuracy in predicting older adults' desire for life-sustaining interventions in the event of decisional incapacity: Is it due in part to erroneous quality-of-life assessments?' *International Psychogeriatrics*, published online 16 March 2017. <https://goo.gl/RQ1ziC>

**N.B.** Additional articles on surrogate decision makers in the context of end-of-life care are noted in the 27 March 2017 issue of Media Watch (#505, pp.3-4).

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

### **A moving target: Medicare beneficiaries coming to the end of long lives**

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 9 May 2017 – The U.S. is in the process of implementing ever-more-fragmented service delivery arrangements for Medicare beneficiaries living with progressive, eventually fatal, advanced illnesses and disabilities. Few outpatient physicians manage their hospitalized patients. New specialists in palliative care consult to settle goals-of-care and advise about symptom management, but they rarely provide ongoing primary care around the clock. Hospice promises to stay with the individual and family through death and bereavement – but hospice serves most enrollees only for 1 or 2 weeks. Hospice programs now often discharge very sick and disabled individuals when they live too long, thereby abrogating the promise of continuity. The Program of All-Inclusive Care of the Elderly (PACE) rarely discharges participants, providing thoroughly comprehensive services to the end of life for elderly persons eligible for Medicaid and living with disabilities, but PACE serves only approximately 38,000 participants nationwide, which is a very small proportion of affected people. Outside of PACE and hospice, very sick and disabled people in their last phase of life usually see many different doctors, often in the emergency department and specialty consultation, without clear or comprehensive care plans and without the support that they and their families need. <https://goo.gl/lmQSmC>

Noted in Media Watch 23 January 2017, #496 (p.9):

- *JOURNAL OF AGING & SOCIAL POLICY* | Online – 13 January 2017 – ‘**A focus on the Program of All-Inclusive Care for the Elderly (PACE).**’ Research has demonstrated that non-profit PACE provides quality, cost-effective community-based care to older adults who would otherwise require a nursing home-level of care. The authors argue that there is not enough evidence to conclude that for-profit PACE provides the same quality of care as existing non-profit operators. <https://goo.gl/8XPSND>

### **Palliative care at the doorstep: A community-based model**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(3):282-286. This article describes a community-based palliative care (PC) program developed to provide care to patients with advanced illness. The mission, model of care and program evolution are outlined; patient demographics, care settings, and co-morbid diseases are reported. The average and median lengths of stay for patients who eventually transitioned to hospice care from 2012 to 2015 are compared with the affiliated hospice’s total population and with national averages. Patients receiving community-based PC for a diagnosis of advanced illnesses, and who later transitioned to hospice, had an increased median and total length of hospice stay as compared with other hospice referral sources and with national averages. For patients with advanced illnesses of many types, PC provided in the community setting may lead to earlier identification and referral to hospice ... and with greater support at end of life. <https://goo.gl/dt6GxD>

### **The development of palliative care in Argentina: A mapping study using Latin American Association for Palliative Care indicators**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 May 2017 – The Latin American Association for Palliative Care developed 10 indicators to monitor the development of palliative care (PC). The indicators have been applied across Latin American countries, but have not been used internally. The application of the indicators at the province level led to the identification of inequalities in the development and distribution of services across the country. The provinces in the north-west were identified as the region with the greatest need for development. The main difficulties for healthcare professionals were lack of national service registries, certified PC specialties, and opportunities for continuous training. Further work needs to be carried out to increase the indicators specificity and integrate them in policy design and service delivery. <https://goo.gl/Yqs9Ta>

**N.B.** See ‘Atlas de Cuidados Paliativos de Latinoamérica,’ Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch 7 January 2013, #287, (p.8)] <https://goo.gl/KyNj4i>



## The rewards of predatory publications at a small business school

*JOURNAL OF SCHOLARLY PUBLISHING*, 2017;48(3). This study is the first to compare the rewards of publishing in predatory journals (PJs) with the rewards of publishing in traditional journals. It finds that the majority of faculty with research responsibilities at a small Canadian business school have publications in PJs. In terms of financial compensation, these produce greater rewards than many non-PJs. Publication in PJs is also positively correlated with receiving internal research awards. By improving the understanding of the incentives to publish in PJs, this research aims to contribute to a better-informed debate on policies dealing with these publications. <https://goo.gl/a56XiU>

### Retraction Watch

**When most faculty publish in predatory journals, does the school become “complicit?”**

Discussion with the author of the *Journal of Scholarly Publishing* article: <https://goo.gl/bPjInO>

**N.B.** Additional articles on “predatory journals” are noted in several past issues of Media Watch, most recently 22 March 2017, #505 (p.7); 30 January 2017, #497 (p.14); and, 23 January 2017, #496 (p.1).

## Person-centred care dialectics: Inquired in the context of palliative care

*NURSING PHILOSOPHY* | Online – 12 May 2017 – Although a widely used concept in health care, person-centred care remains somewhat ambiguous. In the field of palliative care (PC), person-centred care is considered a historically distinct ideal and yet there continues to be a dearth of conceptual clarity. Person-centred care is also challenged by the pull of standardization that characterizes much of health service delivery. The conceptual ambiguity becomes especially problematic in contemporary pluralistic societies, particularly in the light of continued inequities in healthcare access and disparities in health outcomes. The authors’ aim was to explicate premises and underlying assumptions regarding person-centred care in the context of PC with an attempt to bridge the apparently competing agendas of individualization versus standardization, and individuals versus populations. The authors’ analysis suggests that person-centred care is an ethical stance, which gives prominence to both suffering and capability of the individual as a person. The dialectic analysis points towards the importance of extending person-centred care to encompass population and societal perspectives and thereby avoiding a problematic tendency of affiliating person-centred care with exclusively individualistic perspectives. Considerations for person-centred PC on micro-, meso- and macro-levels conclude the paper. <https://goo.gl/5BHucE>

### Related

- *JOURNAL OF PUBLIC HEALTH, NURSING & MEDICAL RESCUE* | Online – Accessed 8 May 2017 – ‘**Influence of selected factors on the quality of dying and death in palliative care.**’ The fundamental aim of palliative care (PC) is to achieve good quality of the process of dying and death. However, the interpretation of these issues remains unclear, mainly due to difficulty in determining the ultimate point of PC. That is why it is necessary to verify the constituents of the quality of dying and death. Studies carried out so far have distinguished a number of various factors affecting the quality of dying and death. Most are associated with health care system and include, among others: 1) The timing of referral to a care facility; 2) The availability of care; 3) The management of symptoms; 4) The type of therapy; and, 5) Communication. Other factors include the place of death, autonomy, preparation for death, as well as socio-demographic factors. <https://goo.gl/7ViLjy>

**N.B.** To access full text click on

ARTICLE PDF

## End-of-life care in England

### **New teams chosen for better end-of-life care scheme**

*NURSING TIMES* | Online – 10 May 2017 – Nineteen health and care teams have been chosen to take part in the latest phase of a pioneering programme aimed at improving end-of-life care (EoLC). Last year, the Point of Care Foundation supported eight teams to make improvements to services by delving into patient experiences and finding out what matters most to them and their loved ones. They included some examples of the practical changes that nurses could achieve through the project. For example, a sympathy card from the ward staff to a family member following the death of a patient, with a personalised message from the nurse who cared for that patient, and providing the contact details for the ward sister and matron so that families could initiate contact if they had any questions or feedback. Another involved a swan sticker being placed in medical/nursing notes when end of life (EoL) was recognised. It identified key components in EoLC, provided a checklist and prompt to continue individualised care planning, and promoted a consistent approach among all staff involved in the patients' care. Other examples included nurses regularly attending meetings with families alongside the doctors where EoL is discussed, improved availability of fold-out bed for relatives, as well as tea, coffee and meals available on the ward and long-term parking permits for families, and training on EoLC medication and syringe drivers for nursing staff, with prompts to ensure earlier prescribing. Nineteen teams from a range of trusts, independent providers and a clinical commissioning group will take part in the scheme, funded by the Foundation and supported by National Health Service England. <https://goo.gl/1AhbL7>

### **Battle weary: When discussing cancer, military terminology doesn't help**

*ONCOLOGY NURSING NEWS* | Online – 6 May 2017 – Promotions for cancer centers or fundraisers, as well as conversations between patients and their healthcare providers or loved ones, often focus on the idea of “fighting” or “battling” cancer. But how do these military metaphors, as opposed to the commonly used phrase “cancer journey,” affect the outlook and coping ability of patients? And what do they accomplish when it comes to motivating those without cancer to engage in preventive measures? Carla Remondini, of Scripps Mercy Hospital, in San Diego, California, researched the issue... She learned military language, for the most part, has a negative effect, both on the emotional state of patients and on the level of engagement of others with preventive efforts. And, although the response to military wording can vary from patient to patient, her findings suggest America needs to reframe the language it uses in its public discourse about cancer. Remondini added the importance placed by our society on “fighting” cancer can sometimes compromise treatment decisions. She looked for data on whether the term “cancer journey” produces more desirable outcomes in patients. In some cases it can be associated with patients feeling passive and not engaged. It depends on the patient's individual experience. <https://goo.gl/jOFHbL>

Noted in Media Watch 10 November 2014, #383 (p.8):

- U.K. (England) | *The Independent* – 3 November 2014 – **‘Mind your language: “Battling” cancer metaphors can make terminally ill patients worse.’** Media portrayals of cancer as a “battle to be fought” are leading to feelings of failure and guilt among terminally ill patients, experts in language and end-of-life care have said. Interviews and analysis of blog posts by patients, carers and health professionals led researchers at the University of Lancaster to conclude war metaphors were unhelpful for many patients.<sup>1</sup> <https://goo.gl/G4Fiik>

1. Metaphor in End-of-Life Care Project, Lancaster University, England: <http://ucrel.lancs.ac.uk/melc/>

## **Palliative Care Network Community**

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## **Randomised clinical trial of early specialist palliative care plus standard care versus standard care alone in patients with advanced cancer: The Danish Palliative Care Trial**

*PALLIATIVE MEDICINE* | Online – 12 May 2017 – The Danish Palliative Care Trial ... is a multi-centre randomised clinical trial comparing early referral to a specialist palliative care (SPC) team plus standard care versus standard care alone. The planned sample size was 300. At five oncology departments, consecutive patients with advanced cancer were screened for palliative needs. Patients with scores exceeding a predefined threshold for problems with physical, emotional or role function, or nausea/vomiting, pain, dyspnoea or lack of appetite according to the European Organisation for Research & Treatment of Cancer Quality of Life Questionnaire were eligible. The primary outcome was the change in each patient's primary need ... at 3- and 8-week follow-up... Totally, 145 patients were randomised to early SPC versus 152 to standard care. Early SPC showed no effect on the primary outcome of change in primary need... The sensitivity analyses showed similar results. Analyses of the secondary outcomes, including survival, also showed no differences, maybe with the exception of nausea/vomiting where early specialist PC might have had a beneficial effect. The authors did not observe beneficial or harmful effects of early SPC, but important beneficial effects cannot be excluded. <https://goo.gl/NTwucx>

## **The effects of life review interventions on spiritual well-being, psychological distress, and quality of life in patients with terminal or advanced cancer: A systematic review and meta-analysis of randomized controlled trials**

*PALLIATIVE MEDICINE* | Online – 10 May 2017 – Life review interventions have been used to alleviate psycho-spiritual distress in people near the end of life. However, their effectiveness remains inconclusive. Eight randomized controlled trials met the inclusion criteria. The pooled results suggested a desirable effect of therapeutic life review on the meaning of life domain of spiritual well-being, general and overall quality of life when compared to usual care only. Of the three outcomes examined, only the pooled effect on overall quality of life remained statistically significant at follow-ups up to three months after the intervention. <https://goo.gl/eO5jLY>

## **Palliative care in heart failure: What triggers specialist consultation?**

*PROGRESS IN CARDIOVASCULAR DISEASES* | Online – 5 May 2017 – As a patient-centered holistic discipline focused on improving quality of life and decreasing anguish, palliative care (PC) has a crucial role in the care of heart failure (HF) patients that has been acknowledged by multiple international guidelines. PC can be provided by all members of the HF care team, including but not limited to practitioners with specialty PC training. Unfortunately, despite recommendations to routinely include PC techniques and providers in the care of HF patients, the use of general PC strategies, as well as expert PC consultation, is limited by a dearth of evidence-based interventions in the HF population and the knowledge as to when to initiate these interventions, uncertainty regarding patient desires, prognosis and the respective roles of each member of the care team, and a general shortage of specialist PC providers. This review seeks to provide guidance as to when to employ the limited resource of specialist PC practitioners, in combination with services from other members of the care team, to best tend to HF patients as their disease progresses... <https://goo.gl/l0d2Jn>

### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 May 2017 – ‘**The state of the science on integrating palliative care in heart failure.**’ The authors identified four key research priorities to improve palliative care (PC) for patients with heart failure (HF) and their families: 1) To better understand patients' uncontrolled symptoms; 2) To better characterize and address the needs of the caregivers of advanced HF patients; 3) To improve patient and family understanding of HF disease trajectory and the importance of advance care planning; and, 4) To determine the best models of PC, including models for those who want to continue life-prolonging therapies. <https://goo.gl/NSGrDZ>

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Noted in Media Watch 8 May 2017, #511 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 May 2017 – ‘**Supportive cardiology: Moving palliative care upstream for patients living with advanced heart failure.**’ Patients living with advanced heart failure (HF) have difficulty in accessing palliative care (PC) supports, which can result in unnecessary suffering as their HF progresses and they near end of life (EoL). This is, in part, due to a lack of research, helping clinicians to identify patients who are approaching EoL. In addition, the unpredictable nature of illness progression often precludes access to most EoL resources in our current prognosis-dependent healthcare system. <https://goo.gl/iFC2Ab>

Noted in Media Watch 24 April 2017, #509 (p.11):

- *JOURNAL OF CARDIOLOGY* | Online – 17 April 2017 – ‘**Potential palliative care quality indicators in heart disease patients: A review of the literature.**’ The authors summarize potential categories of quality indicators in heart disease: 1) Presence and availability of a palliative care (PC) unit, PC team, and outpatient PC; 2) Human resources such as number of skilled staff; 3) Infrastructure; 4) Presence and frequency of documentation or family survey; 5) Patient-reported outcome measure data and disease-specific patient quality of life; 6) Questionnaires and interviews about the quality of PC after death, including bereaved family surveys; and, 7) Admission-related outcomes such as place of death and intensive care unit length of stay. <https://goo.gl/1yFtCf>

### **Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice**

*PUBLIC HEALTH NURSING* | Online – 10 May 2017 – Vulnerable populations in the U.S. experience disparities in access to advance care planning (ACP) and may have significant unmet health care needs at the end of life (EoL), including unrelieved suffering. People who are homeless have increased morbidity and mortality risks, yet lack opportunities to communicate EoL preferences. This paper includes a narrative literature review of ACP interventions and qualitative investigations into EoL concerns among people experiencing homelessness. Trials of clinician-guided interventions with homeless individuals demonstrated effectiveness in achieving advance directive (AD) completion and surrogate decision-maker designation. EoL concerns among homeless persons included fears of dying alone, dying unnoticed, or remaining unidentified after death. Research participants also reported concerns regarding burial and notification of family members. <https://goo.gl/c8ICHa>

Noted in Media Watch 2 January 2017, #493 (p.18):

- *JOURNAL OF URBAN HEALTH* | Online – 27 December 2016 – ‘**The effect of advance directive completion on hospital care among chronically homeless persons: A prospective cohort study.**’ During the 1-year follow-up period, 38 participants who completed an AD and 37 participants who did not complete an AD had at least one hospitalization. Homeless men who complete an AD through a shelter-based intervention are more likely to have their detailed care preferences documented or used during subsequent hospitalizations. <https://goo.gl/NzLvHN>

**N.B.** Additional articles on end-of-life care for the homeless are noted in several past issues of Media Watch, most recently 3 April 2017, #506 (p.10), 13 March 2017, #503 (p.6); 17 December 2016, #495 (p.1); and, 5 December 2016, #490 (p.6).

### **Ethical considerations and palliative care in patients with amyotrophic lateral sclerosis: A review**

*REVUE NEUROLOGIQUE* | Online – 4 May 2017 – By definition, much of the care provided to amyotrophic lateral sclerosis (ALS) patients is palliative, even though active life-sustaining strategies are available to prolong survival. Healthcare professionals (HPs) must develop communication skills that help patients cope with the inexorable progression of the disease and the inevitability of death. Symptomatic treatments as well as respiratory insufficiency and nutritional life-sustaining therapies must be regularly evaluated as the disease progresses, without losing sight of the burden placed on the patient’s non-professional caregivers.



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The decision-making process regarding tracheostomy with invasive ventilation (TIV) is of greater complexity. Providing full information is crucial. Several long interviews are necessary to explain, discuss and allow assimilation of the information. Also, physicians should be careful not to focus exclusively on the biomedical aspects of disease, as ALS patients generally welcome the opportunity to discuss end-of-life issues with their physicians. Psychological factors, education level and cognitive status (especially the level of executive dysfunction) have a major influence on their decisions. However, as many patients do not complete advance directives with regard to TIV, advance care planning may instead be suggested in anticipation of emergency interventions. This should be discussed by HPs and the patient, and based on the wishes of the patient and caregiver(s), and communicated to all HPs. Many HPs are involved in the management of an ALS patient: they include not only those at ALS centers who provide diagnosis, follow-up and treatment initiation (particularly for respiratory and nutritional care), but also the medical and social care networks involved in disability support and home care. <https://goo.gl/NNqsRx>

**N.B.** English language article.

#### **Selected articles on palliative care for patients living with amyotrophic lateral sclerosis**

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):232-235. **‘Palliative care in chronic and progressive neurological disease: Summary of a consensus review.’** In collaboration with the European Academy of Neurology, a taskforce of the European Association for Palliative Care has produced a consensus review on the development of palliative care for people with chronic and progressive neurological disease. [Noted in Media Watch 3 October 2016 #482 (p.9)]

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

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 September 2014 – **‘Palliative care issues in amyotrophic lateral sclerosis: An evidenced-based review.’** This article provides an evidenced-based review of palliative care options not usually addressed in national and international amyotrophic lateral sclerosis guidelines. [Noted in Media Watch 15 September 2014, #375 (p.7)] <https://goo.gl/lvGY3U>
- *JOURNAL OF NEUROLOGY, NEUROSURGERY & PSYCHIATRY* | Online – 5 February 2011 – **‘Palliative care in amyotrophic lateral sclerosis: Review of current international guidelines and initiatives.’** Despite an international consensus that amyotrophic lateral sclerosis (ALS) management should adopt a multidisciplinary approach, integration of palliative care into ALS management varies considerably across health care systems. [Noted in Media Watch 14 February 2011, #188 (p.8)] <https://goo.gl/yX1uKp>

#### **Chronic illness needing palliative care in Kinshasa hospitals, Democratic Republic of the Congo**

*TROPICAL MEDICINE & HEALTH* | Online – 5 May 2017 – Chronic illnesses are a major public health problem in low-income countries. In the Democratic Republic of the Congo (DRC), few data are available, especially in palliative care. In this context, the present study aimed at describing the patterns of diseases in Kinshasa hospitals as well as risk factors associated with patients’ evolving status and length of hospital stay. The study confirms that patients with a chronic disease condition are frequent in Kinshasa hospitals. They are often referred late to the hospital once they have reached an advanced stage of illness. The most frequent diseases encountered were cardiovascular disease, co-morbidities and AIDS. One third of patients died at the hospital, and more than two thirds of patients were lost to follow-up. The proportion of



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female respondents being hospitalized was higher; their hospital stay was shorter, identical to patients from urban areas. Additional studies are urgently required in different environments of care in order to develop a more detailed inventory of these diseases. These will help implement appropriate healthcare strategies in DRC. <https://goo.gl/f0K2rp>

Noted in Media Watch 7 April 2014, #352 (p.12):

- *MÉDECINE ET SANTÉ TROPICALES* | Online – 1 April 2014 – ‘**Qualitative analysis of palliative care and support in medical practices in Democratic Republic of the Congo.**’ This study shows that health professionals believe that end-of-life care is time-consuming and that the inability to say some things to patients and families generates misunderstandings and concerns likely to prevent the application of palliative care. For them, it is often a futile therapeutic obstinacy, added hygienic care, and neglect of the patient. <https://goo.gl/MuFBnd>

N.B. French language article

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 2 May 2017 – ‘**Suicide and assisted dying in dementia. What we know and what we need to know. A narrative literature review.**’ Evidence-based data on prevalence and risk factors of suicidal intentions and behavior in dementia are as scarce as the data on assisted dying. The present literature review aimed on summarizing the current knowledge and provides a critical discussion of the results. Most studies that had investigated the prevalence and risk factors for suicide in dementia had significant methodological limitations. Large prospective studies need to be conducted in order to evaluate risk factors for suicide and assisted suicide in patients with dementia and persons with very early or pre-symptomatic diagnoses of dementia. In clinical practice, known risk factors for suicide should be assessed in a standardized way so that appropriate action can be taken when necessary. <https://goo.gl/DVbtX>
- *THE LINACRE QUARTERLY* | Online – 3 May 2017 – ‘**Why are suicide rates climbing after years of decline?**’ There is evidence that the increasing rates of suicide can be linked to the legalization of physician-assisted suicide. Factors such as suicide contagion and the increasing positive media reporting on such suicides are also relevant and have led to different standards of treatment for suicidal people who claim the right to have their suicides medically assisted. <https://goo.gl/XD2D2U>
- *UNIVERSITY OF PITTSBURGH LAW REVIEW*, 2017;78(2):329-350. ‘**Building bridges between civil rights movements of people with disabilities and those with terminal illness.**’ The movement for disability rights in the U.S. is grounded on a bedrock commitment to empowering the individual with autonomy and independence. Despite this foundation, a sharp line has been drawn by much of the disability advocacy community when it comes to the autonomy of a mentally competent terminally ill patient to choose a more peaceful death through aid in dying. This exercise of autonomy has largely been opposed by the disability advocacy community. This article proposes that given the common principles shared by these two social justice movements and evidence from two decades of open practice in the U.S. that shows that no risk arises for people with disabilities when aid in dying is available, it is time for the disability advocacy community to re-examine and evolve its position on aid in dying. This evolution has the potential to benefit both advocacy communities. <https://goo.gl/ZDvWf1>

### The experience of bereavement following a physician assisted suicide. What do we know about the needs of these bereaved?

*BEREAVEMENT CARE*, 2017;36(1):8-10. The author explored the experience of bereaved people who had experienced multiple or single deaths of a family member or friend, not less than six months ago, occurring by physician assisted suicide (PAS) taking place in a country that has a legal framework to allow a PAS. It is hoped that the findings will inform professionals working to support those bereaved to access support and services they need. <https://goo.gl/a71Lq4>

## Worth Repeating

### **Hope, positive illusions and palliative rehabilitation**

*PROGRESS IN PALLIATIVE CARE* | Online – 11 February 2014 – In ordinary usage, the word “hope” is clear and unambiguous. But in the palliative care (PC) context it has been amplified, dramatized, glamorized, and spiritualized to the extent that it is no more than a piece of inflated rhetoric. The author offers a simple analysis of a simple word, explains why the inflated sense is unhelpful, shows why hope does not have a straightforward “opposite,” and argues that “hope” is not a name for a metaphysical, psychological, or spiritual something-or-other. However, bewitched by their inflated understanding of “hope,” some PC professionals apparently tell patients and carers what they should hope for – which could hardly be more patronizing – while others use it as a portmanteau term to describe whatever positive health care outcomes take their fancy. The author’s suggestion is that palliative rehabilitation specialists should resist the temptations of inflation and glamorisation, and begin to use the word more precisely, modestly, and transparently. There is no such thing as “hope” the life force, “hope” the inner power, “hope” the universal human phenomenon, or “hope” the theological virtue. [Noted in Media Watch 17 February 2014, #345 (p.14)] <https://goo.gl/GQtH5T>

### 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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3. Links often remain active, however, for only a limited period of time.
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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.

### Media Watch: Online

#### **International**

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

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

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

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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): <https://goo.gl/IOSNC7>

### **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/5d1I9K>

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

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