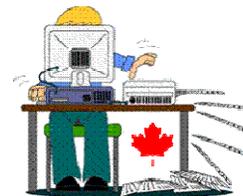


## Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'A snapshot of advance directives in long-term care: How often is "do not" done?' (p.8), in *Healthcare Quarterly*.

## Canada

### Culturally-focused palliative care training on First Nation territory a first, officials say

ONTARIO | *The Sarnia Observer* – 3 February 2017 – A Sarnia-Lambton First Nation is taking steps to make sure its members facing death can spend their last days at home, surrounded by family. Kettle and Stony Point [First Nation] hosted the first-ever Aboriginal-focused palliative care training session for health-care providers ... at the First Nation's health centre. Pallium Canada instructors guided a group of 25 doctors, nurses and other care providers ... through the finer points of end-of-life care. It's the first time the module has been taught with a cultural bent focused on First Nation practices and teachings, officials said. Having health-care providers who are culturally competent in things like the importance of extended family being bedside, and beliefs like the transition to the spiritual world, is important, said Doug George, a community advisor and traditional knowledge keeper who helped open the workshop with information about those cultural practices and beliefs. It also means members don't have to necessarily travel out of the community to hospital. <https://goo.gl/zfi8ld>

### Selected articles on end-of-life care for First Nations (i.e., indigenous) peoples in Canada

- *INTERNATIONAL JOURNAL OF INDIGENOUS HEALTH*, 2016;11(1):50-74. 'Coming home to die: Six Nations of the Grand River Territory develops community-based palliative care.' This paper describes the development and implementation of a community-based palliative care (PC) program in Six Nations of the Grand River Territory, Ontario, Canada. Six Nations' innovative program is grounded in a vision to provide access to quality PC at home and incorporate Haudenosaunee traditional teachings. [Noted in Media Watch 11 July 2016, #470 (p.14)] <https://goo.gl/im094P>
- ONTARIO | CBC News – 24 September 2015 – 'Palliative care poor in First Nations communities, researcher says.' Choosing to live out their last days at home is not an option for many First Nations people. Mary Lou Kelley, a professor at Lakehead University, says federal health care dollars that would help First Nations people receive end-of-life care at home have not kept up with the increasing demand. [Noted in Media Watch 28 September 2015, #429 (p.1)] <http://goo.gl/2DJKB5>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 15 June 2015 – 'Indigenous people's experiences at the end of life.' The findings of this study provide a beginning to an understanding of the end-of-life experiences of indigenous peoples. More research is critical if palliative care services, the healthcare system, and healthcare providers are to reduce barriers to "preparing the spirit" for the journey at the end of life. [Noted in Media Watch 22 June 2015, #415 (p.14)] <http://goo.gl/i2DeQU>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *The Globe & Mail* – 2 February 2017 – ‘How do you put a price on medical aid in dying?’ Assessing seriously ill patients and helping them to die is not as technically complex as brain or heart surgery, but neither is it as straightforward as diagnosing ear aches or performing checkups. Putting a dollar value on medical aid in dying (MAID) is challenging, particularly at a time when provincial governments are trying to rein in what they spend on doctors. Supporters of assisted dying fear that if the permanent fees are set too low, eligible patients could struggle to find doctors willing to help them end their lives. British Columbia’s interim fee for a MAID assessment is a flat rate of \$100.25, while the fee for MAID provision by family doctors is \$125.74 per hour, up to a maximum of 3½. The latter fee covers everything involved in helping a patient to die: prescribing the drugs, picking the drugs up from the pharmacy, spending time with patients and families explaining the procedure, and obtaining final consent, administering the drugs and filing follow-up paperwork with the coroner’s office... <https://goo.gl/OntNYZ>

### Specialist Publications

‘Medical assistance in dying: Controlling the timing of one’s own death’ (p.17), in *BC Medical Journal*.

‘Medical assistance in dying: Living with dignity until life naturally ends’ (p.17), in *BC Medical Journal*.

## U.S.A.

### On National Women Physicians Day, a reminder that women save more lives for less pay

*FORBES* | Online – 3 February 2017 – National Women Physician Day [3 February 2017] honors the birthday of Elizabeth Blackwell [1821-1910], the [first licensed] U.S. primary woman physician, but also the work of the millions of doctors who’ve since followed in her at times arduous footsteps. Launched last year, the now nationally recognized holiday also draws attention to women’s triumphant success rates in the medical field, and to their chronically stunted recognition and compensation therein. According to research, that dedication to superior doctor-patient communication pays off – if not in dollars, then in lives. [A recent] study found that female doctors were simply superior at treating patients in the studied age group than their male counterparts were, even after every practitioner or patient factor was considered, and that if male doctors could somehow take a leaf out of their female peers’ medical book, upwards of 32,000 deaths could be avoided each year among Medicaid recipients alone.<sup>1</sup> To explain this vital discrepancy, researchers pointed to women physicians’ greater tendency to provide preventive care and counseling, and to “have a more patient-centered communication style, more encourag-

ing and reassuring, and have longer visits than male physicians.” <https://goo.gl/av9gbh>

### From the archives

#### **Physician gender effects in medical communication: A meta-analytic review**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2002;288(6):764-756. Female primary care physicians engage in more communication that can be considered patient-centred and have longer visits than their male colleagues. They demonstrate higher levels of smiling and head nods and awareness of non-verbal communications. <https://goo.gl/11h84j>

#### **Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients**

*PALLIATIVE MEDICINE*, 2000;14(4):287-298. Over the three groups [studied], female physicians were more likely to support patient-based decision making as compared to their male colleagues. Future research should attempt to better characterize this difference. <https://goo.gl/N58hX6>

1. ‘Comparison of hospital mortality and readmission rates for Medicare patients treated by male vs. female physicians,’ *Journal of the American Medical Association*, published online 19 December 2016. <https://goo.gl/2yb7KR>

## Florida Hospital closing small, unique hospice

FLORIDA | *The Orlando Sentinel* – 2 February 2017 – For the past six years, a quaint, 6-room home called the Robison Residence has been providing hospice care to Central Florida’s low-income and homeless patients. The one-story house is part of Florida Hospital’s Hospice of the Comforter in Altamonte Springs. It’s also one of the very few free-standing hospice residential facilities in Florida. But on 1 March, after six years, the residence is ceasing operations. Florida Hospital officials said they decided to close the hospice because it has remained a financial burden to Hospice of the Comforter... Another reason, they said, is Central Florida’s growing support for homeless individuals. <https://goo.gl/dmtH43>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HAWAII | *The Hawaii Tribune-Herald* (Hilo) – 29 January 2017 – ‘**Hawaii Medical Association shifts toward accepting end of life legislation.**’ The Association will not oppose passage of a “death with dignity” bill this legislative session. The association has gotten more comfortable with the idea of such legislation, although it has yet to offer direct support. “Historically, we’ve been opposed to this,” said Executive Director Dr. Christopher Flanders. But, with the development of hospice care, the addition of safeguards to bills under consideration, and the ability of doctors to opt out, Flanders said, “sometimes the writing’s on the wall, and we have to accept that.” <https://goo.gl/6YMxBS>

## International

### Grieving couple use CuddleCot to spend 16 days caring for their baby after she died

U.K. (England) | *The Daily Telegraph* – 1 February 2017 – Charlotte Szakacs, 21, and her husband Attila Szakacs, 28, were given the devastating news their baby girl Evlyn had a debilitating chromosome abnormality after a 20-week scan in September 2016. When Evlyn was born on 13 December at Leeds General Infirmary weighing 5lbs 5oz she had an underdeveloped brain which was completely smooth, narrow airways in her nose and lungs and a narrow aorta. And despite battling against the odds for four weeks, the child passed away in her parents’ arms on 10 January at Martin House Hospice in Wetherby, Yorks. Paint technician Charlotte and engineer Attila stayed at the hospice for 12 days while Evlyn was kept in a refrigerated CuddleCot and were allowed to take her out for family walks – before the first-time parents took Evlyn home for four days before her funeral on 26 January. Dr. Clea Harmer, chief executive at stillbirth and neonatal death charity Sands, said: “A cold cot allowed Evlyn’s parents to spend extra time with their daughter after she had died, and some parents tell us that spending time with their babies at home or in hospital can help them with the grieving process.” <https://goo.gl/RxE33r>

**N.B.** A CuddleCot is a machine that pumps cold water through a pad lining a bassinet, keeping a baby cool and slowing the changes that occur after death. **BRA**

### Specialist Publications

‘Palliative care in New York State nursing homes: A descriptive study’ (p.14), in *American Journal of Hospice & Palliative Medicine*.

‘How states can expand access to palliative care’ (p.7), in *Health Affairs*.

‘Resource use and Medicare costs during lay navigation for geriatric patients with cancer’ (p.7), in *JAMA Oncology*.

‘Cost analysis of a prospective multi-site cohort study of palliative care consultation teams for adults with advanced cancer: Where do cost-savings come from?’ (p.7), in *Palliative Medicine*.

## U.K. Bereavement Support Payment

### **Young and bereaved – and now facing cuts to crucial financial support**

U.K. | *The Guardian* – 29 January 2017 – The government revealed earlier this month how the current system of bereavement support payments will change in April in order, it says, to modernise the structures. But it has provoked a barrage of opposition and criticisms that many parents who are widowed after 5 April will be far worse off. The drop in income these families will suffer means many parents will be forced to increase their working hours while their children are still trying to cope with their loss, bereavement charities predict. Childhood Bereavement Network suggests 91% of widowed parents will be supported for a shorter period of time than they would under the current system... <https://goo.gl/Gsu3yL>

### **Specialist Publications**

**‘Funding models in palliative care: Lessons from international experience’** (p.15), in *Palliative Medicine*.

## **Specialist Publications**

### **Seeking legitimacy for *DSM-5*: The bereavement exception as an example of failed process**

*AMA JOURNAL OF ETHICS*, 2017;19(2):192-198. In 2013 the American Psychiatric Association (APA) published the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. Even before publication, *DSM-5* received a torrent of criticism, most prominently over removal of the “bereavement exclusion” for the diagnosis of major depression. The authors of this article argue that while the APA can claim legitimate authority for deciding scientific questions, it does not have legitimacy for resolving what is ultimately a question of ethics and public policy. They show how the “accountability for reasonableness” framework for seeking legitimacy in health policy could have been used to achieve a better resolution of the conflict than actually occurred. <https://goo.gl/NQRonp>

### **Providing palliative care to patients with cancer: Addressing the needs in Kenya**

*ASIA-PACIFIC JOURNAL OF ONCOLOGY NURSING*, 2017;4(1):45-49. Cancer is the third highest cause of death in Kenya, preceded by infectious and cardiovascular diseases, and in most cases, diagnosed in later stages. Nurses are the primary caregivers, assessing and managing these patients in the clinic, in inpatient settings, and in rural and remote communities. While cancer rates remain high, the burden to the patient, the caregiver, and society as a whole continues to rise. Kenya's poverty complicates cancer even further. Many Kenyans are unaware of cancer's signs and symptoms, and limited diagnostic and treatment centers are available. Despite these barriers, there is still hope and help for those in Kenya, who suffer from cancer. The World Health Organization has stated that palliative care (PC) is a basic human right and nurses providing this care in Kenya are making efforts to support cancer patients' ongoing needs, in order to promote compassionate PC and prevent suffering. The purpose of this paper is to address the PC needs of patients with cancer in Kenya by providing education to nurses and influencing health-care policy and education at micro and macro levels. A case study weaved throughout will highlight these issues. <https://goo.gl/UEShdq>



Cont.

Noted in Media Watch 5 September 2016, #478 (p.9):

- *eCANCERMEDICALSCIENCE* | Online – Accessed 30 August 2016 – ‘**Kenya Hospices & Palliative Care Association: Integrating palliative care in public hospitals in Kenya.**’ Eleven provincial hospitals across the country have now integrated palliative care (PC) services... Over 220 healthcare providers have been trained, and approximately 30,000 patients have benefited from these services. The Association is now working with the Ministry of Health Kenya to integrate PC services in 30 other county hospitals across the country, ensuring more availability and access to more patients. Other developing countries can learn from Kenya’s successful experience. <http://goo.gl/9huLYb>

Noted in Media Watch 21 December 2015, #441 (p.12):

- *HEALTH & HUMAN RIGHTS JOURNAL*, 2015;17(2):149-165. ‘**Evaluating a human rights-based advocacy approach to expanding access to pain medicines and palliative care: Global advocacy and case studies from India, Kenya, and Ukraine.**’ The involvement of mainstream human rights organizations in advocacy around access to palliative care (PC) has lent credibility and specificity to the concept and helped generate a broad acceptance that PC is indeed a right. The authors efforts to advance an understanding and acceptance of access to PC as an element of the right to health were aided by recognition of the relationship between this right and two fundamental principles long recognized within human rights movements. <http://goo.gl/0Nel42>

### **Which patients with advanced respiratory disease die in hospital? A 14-year population-based study of trends and associated factors**

*BMC MEDICINE* | Online – 1 February 2017 – Hospital deaths from chronic obstructive pulmonary disease (COPD) and interstitial pulmonary diseases (IPD) fell by 3-6% in the 8 years following the introduction of the end-of-life care (EoLC) strategy; however, those with multi-morbidity did not show a fall in hospital deaths. Multi-morbidity, deprivation, living in cities, and living in London play a greater role in affecting where people with IPD die than those with COPD. Age and sex affect the chance of hospital death differently for COPD and IPD. Being married rather than single, widowed or divorced made hospital death more likely in COPD, but not in IPD. The results suggest that the EoLC strategy may have helped to shift some deaths out of hospital for people with respiratory disease, but more integrated approaches of earlier palliative care are needed, targeting those at highest risk, especially with multi-morbidity, and in deprived areas and cities. Further initiatives and trials are needed to understand and to improve the quality of care for people both in hospital (where most people are dying) and at home. <https://goo.gl/MVUvCG>

**N.B.** Additional articles on palliative care and chronic obstructive pulmonary disease are noted in past issues of Media Watch, e.g., 2 January 2017, #493 (p.9).

### **Supporting relatives and carers at the end of a patient’s life**

*BRITISH MEDICAL JOURNAL* | Online – 2 February 2017 – All doctors, irrespective of their specialty or the setting in which they work, will care for patients who die. Around half of all deaths occur in hospitals. Evidence suggests that the quality of communication around this process is poorer in hospitals than in other settings, according to responses from relatives who have experienced bereavement. Over half of National Health Service complaints concern care of the dying. This article discusses how to best support relatives and carers at the end of a patient’s life. While the focus is on the hospital setting, the principles are applicable to community and care home settings. In this article, “relative” encompasses family members, care givers, and those close to the patient. The article presumes throughout that the patient has given consent for information to be shared with relatives. <https://goo.gl/68QwIF>



#### **Media Watch Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.18.

## The right to mourn in dementia: To tell or not to tell when someone dies in dementia day care

*DEATH STUDIES* | Online – 31 January 2017 – People with dementia (PwD) attending dementia day care often experience the death of others. Little research exists regarding whether PwD should be informed of the death, and if so, how? In this qualitative research, the authors explored, through semi-structured interviews, the beliefs and practices of 52 staff members of adult day centers for PwD about these issues. Themes that emerged are that many staff members feel their clients have emotional capacity to mourn, despite their cognitive impairments. There are many different ways to tell PwD about the death of others. Each case should be judged individually. <https://goo.gl/BhJJbW>

### Related

- *DEMENTIA*, 2017;16(1):67-78. ‘**Dementia grief: A theoretical model of a unique grief experience.**’ To date, theoretical models and therapeutic interventions with grief in caregivers have not adequately considered the grief process, but instead have focused on grief as a symptom that manifests within the process of caregiving. The authors introduce the Dementia Grief Model, describe the unique characteristics of dementia grief, and present the psychological states associated with the process of dementia grief. <https://goo.gl/4O243S>

## Geriatric Education Utilizing a Palliative Care Framework

*GERONTOLOGY & GERIATRICS EDUCATION* | Online – 27 January 2017 – The dramatic growth of persons over 65 and the increased incidence of multiple, chronic illness has resulted in the need for more comprehensive healthcare. Geriatrics and palliative care are medical specialties pertinent to elderly, yet neither completely addresses the needs of older adults with chronic illness. Interprofessional faculty developed Geriatric Education Using a Palliative Care Framework (GEPaC) to teach an integrated approach to care. Interactive online modules use a variety of instructional methods, including case-based interactive questions, audio-visual presentations, reflective questions, and scenario-based tests. Modules are designed for online education and/or traditional classroom and have been approved for continuing medical education. Pre- and post-test scores showed significant improvements in knowledge, attitudes and skills. Participants were highly satisfied with the coursework’s relevance and usefulness for their practice, and GEPaC prepares them to address needs of older adults for disease and symptom management, communicating goals of care, and supportive/compassionate care. <https://goo.gl/KZn9Cw>

### Selected articles on common ground in geriatrics and palliative care

- *BMC PALLIATIVE CARE* | Online – 11 May 2016 – ‘**A qualitative exploration of the collaborative working between palliative care and geriatric medicine: Barriers and facilitators from a European perspective.**’ Considering the growing need of palliative care (PC) for older people, improving knowledge about PC principles and acquainting general PC skills of geriatricians and other health care professionals is of crucial importance. However, whilst there are good examples of close clinical working between the disciplines, e.g., multidisciplinary team working, there is very limited collaboration in education and policy. [Noted in Media Watch 16 May 2016, #462 (p.8)] <http://goo.gl/8cyuQg>
- *THE GERONTOLOGIST*, 2015;55(3):503-505. ‘**Guidance at the juncture of palliation and old age.**’ Notwithstanding their expertise in caring for persons in the final decades of life, some gerontologists remain unfamiliar with the effective palliation of symptoms for older adults with life-limiting or chronic, debilitating conditions. Similarly, palliative care (PC) providers have advanced health care practices to maximize comfort, function, and quality of life for persons (of all ages) who are living with life-threatening diagnoses. [Noted in Media Watch 8 June 2015, #413 (p.11)] <http://goo.gl/7fJYeF>
- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 21 February 2014 – ‘**Regardless of age: Incorporating principles from geriatric medicine to improve care transitions for patients with complex needs.**’ This article provides a framework for incorporating geriatrics principles into care transition activities by discussing: 1) Identifying factors that make transitions more complex; 2) Engaging care “receivers” and tailoring home care to meet patient needs; 3) Building “recovery plans” into transitional care; 4) Predicting and avoiding preventable readmissions; and, 5) Adopting a palliative approach, when appropriate, that optimizes patient and family goals of care. [Noted in Media Watch 24 February 2014, #346 (p.9)] <http://goo.gl/U2GhgM>

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

### How states can expand access to palliative care

*HEALTH AFFAIRS* | Online – 30 January 2017 – Access to palliative care (PC) for people with serious illness ... has expanded greatly over the last decade due to a rapidly increasing aging population with complex and costly care needs; a growing evidence base demonstrating that PC improves patient and caregiver quality of life and reduces overall cost; and, an accelerated transition to payment models that reward value over volume. As the new administration strategizes how to repeal and replace the Affordable Care Act – and how to shift risk and responsibility for health care payment to states, health care organizations, commercial payers, providers, and patients and families themselves – we expect state policy to play a more dominant role in determining who gets care, how it is paid for, and how to set and achieve a standard of quality and safety. Of great concern is the impact of a potentially destabilized insurance market that could lead to loss of coverage for people with the greatest need for health care services, such as those with serious illness. Outcomes for this group are especially important as a majority of the seriously ill fall into the top 5% of the population that accounts for 50% of total health care expenditures. Given the states' role in funding safety-net programs, as well as the fact that historical precedent and early signs indicate a push towards both more privatization of Medicare and Medicaid and greater state control in health care delivery and payment, states should consider levers to expand local access to PC. <https://goo.gl/IQeUtl>

Noted in Media Watch 5 October 2015, #430 (p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 September 2015 – ‘**The growth of palliative care in U.S. hospitals: A status report.**’ This study demonstrates continued steady growth in the number of hospital palliative care (PC) programs in the U.S.,<sup>1</sup> with almost universal access to services in large U.S. hospitals and academic medical centers. Nevertheless access to PC remains uneven and depends on accidents of geography and hospital ownership. <http://goo.gl/h3RAdY>

1. ‘America’s Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,’ Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. <https://reportcard.capc.org/>

### Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 2 February 2017 – ‘**Death of outrage over talking about dying.**’ The authors examined public reaction to the proposed Center for Medicare & Medicaid Services rule reimbursing physicians for advanced care planning (ACP) discussions with patients. However, ACP is not widely used in the U.S., potentially reducing the use of palliative care. Reimbursing ACP discussions between physicians, patients and their family has the potential to have a large impact on the quality of life of persons near death, which can greatly impact public health and the comfort in dealing with our ultimate demise. <https://goo.gl/mSulGu>
- *JAMA ONCOLOGY* | Online – 26 January 2017 – ‘**Resource use and Medicare costs during lay navigation for geriatric patients with cancer.**’ Lay navigators in the University of Alabama Health System Cancer Community Network Patient Care Connect Program (PCCP) support patients with cancer from diagnosis through survivorship to end of life. They empower patients to engage in their health care and navigate them through the increasingly complex health care system. The combination of reduced use of resources and increased hospice use achieved by the PCCP is consistent with ... palliative and supportive care interventions... <https://goo.gl/qgdBG0>
- *PALLIATIVE MEDICINE* | Online – 3 February 2017 – ‘**Cost analysis of a prospective multi-site cohort study of palliative care consultation teams for adults with advanced cancer: Where do cost-savings come from?**’ Cost-savings from early palliative care (PC) accrue due to both reduced length of stay and reduced intensity of treatment, with an estimated 63% of savings associated with shorter length of stay. A reduction in day-to-day costs is observable in the days immediately following initial consult but does not persist indefinitely. A comparison of early and late PC consultation team cost-effects shows negligible difference once the intervention is administered. Patient- and family-centred discussions on goals of care and transition planning initiated by PC consultation teams may be at least as important in driving cost-savings as the reduction of unnecessary tests and pharmaceuticals identified by previous studies. <https://goo.gl/KoKFSw>

## A snapshot of advance directives in long-term care: How often is “do not” done?

*HEALTHCARE QUARTERLY*, 2017;19(4):10-12. There is an opportunity to raise awareness with residents and families about advance care planning. Research shows that a decision to transfer a resident to hospital despite the person’s advance wishes is often made by family members (Biola *et al*, 2010). The stress of a hospital transfer and potential risk of infection can often outweigh the perceived benefits of treatment (Konetzka *et al*, 2008; Ouslander & Maslow, 2012). Sometimes, serious infections such as pneumonia can be treated in long-term care (LTC) facilities, often with better outcomes for these patients (Fried *et al*, 1997; Thompson *et al*, 1997). That being said, it is up to residents and their families to decide on the best course of action. Although a lot of progress has been made, potentially avoidable hospitalizations can be further reduced in LTC settings. Initiatives to improve the quality of LTC and avoid unnecessary hospitalizations, such as Ontario’s Residents First initiative (Health Quality Ontario), appear to be bearing fruit; hospitalizations among all LTC residents dropped significantly – by about 50% – over the 3 years of this study period. Results also suggest that palliative care (PC) services can be enhanced in LTC. PC is one of the few areas that did not experience a decline in hospital transfers over the study period. Although many jurisdictions in Canada have initiatives under way to improve end-of-life services out of hospital, few nursing homes have formal PC programs (Quality Hospice Palliative Care Coalition of Ontario, 2010; Williams *et al*, 2010). <https://goo.gl/qKkNOH>



Canadian Institute  
for Health Information  
Institut canadien  
d’information sur la santé

**N.B.** ‘A snapshot of advance directives in long-term care: How often is “do not” done?’ Canadian Institute for Health Information (‘Analysis in Brief’ first published in May 2016). <https://goo.gl/L2ljEr>

### Related

- *BMC MEDICAL ETHICS* | Online – 2 February 2017 – ‘**Critical appraisal of advance directives given by patients with fatal acute stroke: An observational cohort study.**’ Advance directives (ADs) should enable individuals to have their wishes respected in future treatment decisions in case of incapacity. Yet, the prevalence of ADs among patients who die from acute stroke is still low. In this study, less than half of the existing ADs were considered to be applicable for severe acute stroke. From the clinicians’ point of view, the use of standardized ADs is not likely to support the intended autonomy of patients. There is a need to foster educational programs for the general public about advance care planning, especially in the light of the large number of stroke-related conditions in the aging population. <https://goo.gl/gtA4rJ>



### [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>



### Closing the Gap Between Knowledge & Technology

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

## End-of-life care in Ethiopia

### **An ethnography of managing emotions when talking about life-threatening illness**

*INTERNATIONAL NURSING REVIEW* | Online – 2 February 2017 – Ethiopia, as a developing country, had few resources for caring for those requiring end-of-life care. However, palliative care (PC) was supported by local champions in Ethiopia and by the Federal Ministry of Health. This ethnographic study was concerned with how dying patients, PC staff and family caregivers communicate about life-threatening illness in a PC setting in Ethiopia. Although PC staff create openness in communication with patients and family caregivers about terminal illness and dying, ultimately they deferred to family wishes about significant news disclosures, in order to avoid upset. Family caregivers were found to avoid disclosing news of a terminal illness to their family member and wished to keep the patient in closed awareness. In contrast, an open awareness context existed between PC staff and family caregivers. In managing truth telling in different cultural settings, medical and nursing staff as well as health policy makers need to take into account the various awareness contexts highlighted in this study. PC staff should consider how actions such as protecting patients from upset may inadvertently deny the patient the right to exercise control. Health policy makers should ensure that the design and implementation of PC services should not be a whole-sale adoption of Western style services but ensure that such services are adapted to reflect the religious, cultural and social needs of the community. Foreign workers and volunteers who deliver PC services and education in Ethiopia should reflect local religious and cultural sensitivities. <https://goo.gl/zM0di1>



### **Branding palliative care units by avoiding the terms “palliative” and “hospice”: A nationwide study in Taiwan**

*INQUIRY: THE JOURNAL OF HEALTH CARE ORGANIZATION, PROVISION & FINANCING* | Online – 24 January 2017 – The term “palliative care” (PC) has a negative connotation and may act as a barrier to early patient referrals. Rebranding has thus been proposed as a strategy to reduce the negative perceptions associated with PC. For example, using the term “supportive care” instead of “palliative care” in naming PC units has been proposed in several studies. In Taiwan, terms other than “palliative” and “hospice” are already widely used in the names of PC units. With this in mind, this study investigated the characteristics of PC unit names in order to better understand the role of naming in PC. The authors found a clear phenomenon of avoiding use of the terms “palliative” and “hospice” in the naming of PC units, a phenomenon that reflects the stigma attached to the terms “palliative” and “hospice” in Taiwan. At the time of the study (September, 2016), there were 55 PC units in Taiwan. Only 20% of the PC unit names included the term “palliative,” while 25.2% included the term “hospice.” Religiously affiliated hospitals were less likely to use the terms “palliative” and “hospice.” There was also a lower prevalence of use of the terms “palliative” and “hospice” for naming PC units in private hospitals than in public hospitals. <https://goo.gl/9Z6xAu>

**N.B.** Taiwan was ranked 6th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/nuPWll>

## Promoting end-of-life discussions in advanced cancer: Effects of patient coaching and question prompt lists

*JOURNAL OF CLINICAL ONCOLOGY* | Online – 30 January 2017 – Most patients with advanced cancer say they want honest, sensitive communication about end-of-life issues. These conversations help patients and their families prepare, make informed decisions, and avoid potentially burdensome aggressive medical treatments near death. Yet, patients are often misinformed about cancer survival and curability, and those with over-optimistic prognosis estimates are more likely to die in a hospital and receive burdensome aggressive care. Patients often do not disclose their concerns and vary in the amount of information they want about the disease, prognosis, and treatment options, whereas physicians often do not know or enact patient preferences about end-of-life issues. Interventions to promote communication in cancer settings have targeted patients and physicians. Randomized controlled trials in early cancer and palliative care have shown that question prompt lists (QPLs) – structured lists of questions given to patients before consultations – help patients with cancer and their caregivers ask more questions, particularly if the physician also encour-

ages and endorses the QPL. In addition, a tailored pre-visit educational coaching intervention (that did not involve QPLs) helped patients with cancer communicate concerns about pain. Meanwhile, an oncologist intervention that used audio recordings with tailored feedback positively influenced patient trust and oncologist responsiveness to patient emotions. Yet, no randomized trials have evaluated interventions directed toward both oncologists and their patients with advanced cancer who are not yet receiving palliative or hospice care. <https://goo.gl/cm068b>

### Learning to drive – early exposure to end-of-life conversations in medical training

*NEW ENGLAND JOURNAL OF MEDICINE*, 2017; 376(5):413-415. Sent to visit a chronically ill patient at home, a medical student finds that his inexperience can be a strength. Instead of worrying about the right words and how to say them, he learns how to listen – exactly what the patient needs as she faces end-of-life decisions. <https://goo.gl/VhYfgC>

## End-of-life care and opioid use in India: Challenges and opportunities

*JOURNAL OF GLOBAL ONCOLOGY* | Online – 25 January 2017 – In 2011, the WHO estimated that 20 million people required end-of-life palliative care (PC), of whom 78% lived in low- and middle-income countries. In a country like India, which contains 17.5% of the world population, end-of-life PC is almost non-existent...<sup>1</sup> According to estimates from India, approximately 10 million people may require PC services, of whom 1 million have cancer and 7 million have other life-limiting conditions. It is estimated that the yearly incidence of cancer in India will increase from 1 million in 2015 to 1.7 million by 2035. The 2015 Global Burden of Disease data estimated that 675,000 persons die with a diagnosis of cancer every year in India. The gravity of the situation could not be any more evident than in the fact that more than 26,000 individuals suffering from cancer, AIDS, paralysis, and other

chronic illnesses ended their life in 2013, accounting for nearly 20% of all deaths caused by self-harm in India. <https://goo.gl/0AW8jd>

### Extract from *Journal of Global Oncology* article

In India, poppy plants are grown only in three states and are under strict government licensing. The government-owned company Opium & Alkaloid Works has only two factories processing raw materials from poppy plants into morphine sulphate powder for the entire country. Manufacturers obtain the compound from the factory, which is then converted into tablets and injections. Total morphine consumption in India was a paltry 278 kg in 2014. If a patient with terminal cancer requires 75 mg of morphine per day for pain relief for approximately 90 days, this amount of 278 kg is only sufficient to adequately treat 40,000 patients.

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore. India was ranked 67th of 80 countries surveyed. [Noted in Media Watch 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5>

**N.B.** Additional articles on opioid availability and use in India are noted in past issues of Media Watch, e.g., 25 April 2016, #459 (p.8).

## **A matter of life and death: Knowledge about the body and concept of death in adults with intellectual disabilities**

*JOURNAL OF INTELLECTUAL DISABILITY RESEARCH*, 2017;61(1):89-98. An increased awareness of how people with intellectual disabilities (ID) understand death and dying is necessary in supporting life-long learning, post-bereavement support, and planning end-of-life care. Previous research suggests that adults with ID have a limited or “patchy” understanding of the basic biological components of death. However, the relationship between biological understanding of how the body works and conceptualisation of death remains unexplored in this population. The results [of this study] support previous studies suggesting that understanding of death in adults with ID varies from partial to full comprehension and is associated with level of ID. The study highlights the relationship between knowledge about the goal of human body functioning and death comprehension in adults with ID. The potential that learning to adopt a “vitalistic” approach to human functioning may have on the acquisition of a greater understanding of death and dying, understanding illness and supporting end-of-life planning is discussed. <https://goo.gl/ExE91T>

Noted in Media Watch 19 December 2016, #492 (p.13):

- *NURSING & PALLIATIVE CARE*, 2016;1(5):118-123. ‘Literature review of best health and social care practices for individuals with intellectual disabilities encountering the end of life.’ The authors identified four emergent themes: 1) End-of-life care (EOLC) approaches, policies and guidelines; 2) Challenges experienced by members of the health and social care team; 3) The importance, challenges and benefits of communication; and, 4) Examples of good practice including rounded EOLC that emphasises working collaboratively and inclusively with family and friends. Further, overall findings revealed that there was an absence of policies, procedures and guidelines governing these critical EOLC practices, including decision making processes. <https://goo.gl/GHeJug>

**N.B.** Additional articles on end-of-life care for people living with intellectual disabilities are noted in this issue of Media Watch.

## **Chaplains working in palliative care: Who they are and what they do**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 February 2017 – Palliative care (PC) programs utilize chaplains to address patients’ spiritual care needs; however, there is no comprehensive description of chaplaincy in PC programs nationally. The authors invited participation [in a national online survey] from hospital-based chaplains belonging to four national professional chaplain associations who spent 15% or more of their working hours with PC teams. They developed a 41-item survey to investigate main outcomes of chaplain demographics, practice information, integration into the PC team, and visit content. The authors report on respondents who were full-time chaplains... Almost half were women (46%), and the majority was Protestant (70%). The average number of PC patients seen per day was 5.2... Half (52%) reported frequently participating in PC rounds. Primary chaplain activities were relationship building (76%), care at the time of death (69%), and helping patients with existential issues or spiritual distress (49%). Over half (55%) reported addressing goals of care 60% of the time or more. This survey provides the first description of chaplains working in PC across the U.S. This study suggests that when chaplains are more involved in PC teams, they provide more comprehensive support to PC patients and their families. <https://goo.gl/hpZOyu>

Noted in Media Watch 20 July 2015, #419 (p.11):

- *JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 13 July 2015 – ‘Recognizing success in the chaplain profession: Connecting perceptions with practice.’ The current investigation examines the communicative hallmarks [i.e., *non-verbal* vs. *verbal hallmarks*] of successful chaplaincy work as articulated by professional chaplains providing spiritual care at the end of life. <http://goo.gl/AyjULC>

## An 11-year study of home hospice service trends in Singapore from 2000 to 2010

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 30 January 2017 – With an increasing emphasis to encourage aging and dying in the community and more attention given to building up the home hospice industry's capacity and capability, it is important to understand the profile of the patients who have been utilizing home hospice services. This also helps to plan and develop similar services in other parts of the world. Patients [studied] had multiple admissions into HHC home hospice as identified in the Electronic Medical Records between 1 January 2000 and 31 December 2010... Of the 25,065 patients in the entire samples, 47.3% were males, 65.2% were married, and 84.3% were Chinese. 50.9% of the patients died at home, 75.5% were referred from public hospitals, 53.9% of primary caregivers were children, and the mean age of the patients was 68.0 years. Among all cancer patients admitted into HHC home hospice, lung cancer (23.6%) was the most common principal diagnosis for admission, followed by colorectal (10.5%) and liver cancers (7.7%). Among non-cancer patients, renal failure (7.0%) was the most common diagnosis. Among male patients admitted into HHC home hospice, lung cancer (29.6%) was the most common diagnosis, followed by liver cancer (10.8%), colorectal cancer (10.0%), and end-stage renal failure (5.5%). For female patients, lung cancer (16.9%) was the most common diagnosis, followed by breast cancer (15.9%), colorectal cancer (11.0%), and end-stage renal failure (8.7%). Ten-year trends of the socio-demographic profile and diagnosis at admission were further analyzed to determine home hospice services utilization and the needs of the home care patients. <https://goo.gl/NYdvcY>

**N.B.** See 'Lien Foundation Survey on Death Attitude.' The survey revealed that while nearly 8 in 10 Singaporeans wish to die at home less than a third of deaths take place in the home. The survey also examined awareness and receptivity towards hospice palliative care, and attitudes towards death & dying. [Noted in Media Watch 14 April 2014, #353 (p.7)] <https://goo.gl/UWCrWr>

## Psychosocial well-being of young people who participated in a support group following the loss of a parent to cancer

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 31 January 2017 – Despite the evidence of unmet support needs among young people who have lost a parent to cancer, only a few support group initiatives have been reported. This observational prospective study explored the psychosocial well-being of young people who participated in support groups at a Swedish specialist palliative care setting. On three occasions, 29 participants, aged 16-28 years, answered questionnaires covering characteristics of the participants, circumstances of the losses, psychosocial well-being of the young people, and their own assessment of the support groups. The support groups attracted mostly young women who were often unprepared for the loss. The living arrangements differed between younger and older participants; however, the loss-related variables did not differ. Significant positive changes were found regarding a sense of meaning in their fu-

ture life and life satisfaction. The helpfulness of the group was assessed as high/very high and the group brought a valuable fellowship with others in a similar situation. Universality and beneficial interactions were reported and strengthened psychosocial well-being developed over time. This change, according to the young people themselves, may be attributed to the group support. The findings are useful for planning interventions to support young people in bereavement in order to enhance their psychosocial well-being. <https://goo.gl/gjCqtF>

CANADIAN  Portail CANADIEN EN SOINS  
**Virtual Hospice** **palliatifs**

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

## Sedation until death: Are the requirements laid down in the guidelines too restrictive?

*KENNEDY INSTITUTE OF ETHICS JOURNAL*, 2016;26(4):369-397. Guidelines that have been published on sedation until death take the following positions: the patient's consciousness should not be lowered more than is necessary for preventing her from suffering; it must be impossible to alleviate the suffering in any alternative way; and, the patient's mere preference for dying peacefully cannot justify the procedure. Some guidelines also stipulate that purely existential suffering cannot do so either. The author discusses the (few) arguments that can be found in the literature for these restrictions. He focuses, in particular, on the argument that it is either a vital interest, or even a duty, of the patient to preserve consciousness as long as possible at all times. None of these arguments turn out to be convincing. On the other hand, deviation from the requirements can be justified only by appealing to the priorities of the patient. These should therefore have been discussed in detail at an earlier stage of the patient's illness. <https://goo.gl/6QeaH4>

### Related

- *EVIDENCE BASED NURSING* | Online – 30 January 2017 – ‘**Second thoughts about palliative sedation.**’ Palliative sedation (PS) is a term used to describe the use of sedative drugs in dying patients to induce a state of decreased or absent awareness (unconsciousness) in order to relieve intolerable suffering from refractory symptoms. Perhaps, for many of us, this conjures up an image of an agitated patient who is rendered unconscious in the last hours of life as a result of the need for repeated doses of sedative drugs. However, in the literature, “palliative sedation” is used more broadly, sometimes as an umbrella term for all levels and patterns of sedation in those close to death. <https://goo.gl/8b33Uy>

### Selected articles on palliative sedation

- *MINERVA ANESTESIOLOGICA* | Online – 22 December 2016 – ‘**Palliative sedation: The position statement of the Italian National Committee for Bioethics.**’ In January 2016 the Italian National Bioethics Committee published a position statement ... related to the use of sedation and analgesia for relief from pain and psychological distress in dying patients. The Committee ... points out the clinical and ethical appropriateness of palliative sedation (PS) as a therapeutic procedure. PS has to be considered today useful, scientifically safe and reliable, and acknowledged as an integral part of good clinical practice [Noted in Media Watch 2 January 2017, #493 (p.19)] <https://goo.gl/NLynP4>
- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 1 July 2016 – ‘**A systematic literature review on the ethics of palliative sedation: An update (2016).**’ In a 2010 review of palliative sedation (PS), the following areas were identified as lacking in consensus: 1) Inconsistent terminology; 2) Its use in non-physical suffering; 3) The ongoing experience of distress; and, 4) Concern that the practice of PS may hasten death. This review looks at the literature over the past 6 years and provides an update on these outstanding concerns. [Noted in Media Watch 11 July 2016, #470 (p.13)] <http://goo.gl/qWxPpk>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: Analysis of international guidelines and position statements.**’ Guidelines, etc., have been published by the American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). [Noted in Media Watch 12 May 2014, #357 (p.6)] <http://goo.gl/IUy00q>

## Developing, implementing and evaluating an end-of-life care intervention

*NURSING OLDER PEOPLE* | Online – 31 January 2017 – Collaborative end-of-life care (EoLC) interventions support care home staff to manage end of life and may enable residents to have choice about their place of death. A two-phase exploratory mixed methods design was used, evaluating the effect of an EoLC toolkit and associated training in care homes, facilitated by a specialist palliative care team. Six care homes in England were recruited to the intervention; 24 staff participated in discussion groups; 54 staff attended at least one training session; and, pre- and post-intervention questionnaires were completed by 78 and 103 staff respectively. Staff confidence in receiving emotional and clinical support and managing EoLC symptoms increased post-intervention, but confidence in discussing death and dying with residents and relatives decreased. Data indicate greater reduction in the number of residents from participating care homes dying in hospital than those from comparison homes. <https://goo.gl/ELtQVD>

### Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 31 January 2017 – ‘**Palliative care in New York State nursing homes: A descriptive study.**’ Hospice is less available than palliative or comfort care programs, with three-fourths of the New York State nursing homes (NH) that responded to a survey providing a palliative care (PC) program. In general, medical directors and physicians were more similar in perspective about the role/impact of PC compared to nursing and others. There was general agreement about the positive impact and role of PC in the NH. Funding and staffing were recognized as barriers to implementing PC. <https://goo.gl/T2V6Gn>
- *BMC MEDICAL EDUCATION* | Online – 31 January 2017 – ‘**Doctors’ learning experiences in end-of-life care – a focus group study from nursing homes.**’ There is a considerable potential for training doctors in end-of-life care in nursing homes, which can be developed and integrated in medical education. This practice based learning arena offers newly qualified doctors close interaction with patients, relatives and nurses, teaching them to perform difficult dialogues, individualize medical decisions and balance their professional role in an interdisciplinary setting. <https://goo.gl/rMZOyu>

### Paediatric palliative care in the U.K.

## End-of-life care for infants, children and young people with life-limiting conditions

*NURSING STANDARD* | Online – 1 February 2017 – According to the Royal College of Paediatrics & Child Health, the U.K. has one of the worst child mortality rates in western Europe, with more than 2,000 children and young people dying in 2012. In addition, it is estimated that about 50,000 children and young people in the U.K. have a life-limiting condition that may need palliative care. <https://goo.gl/jJE19b>

Noted in Media Watch 17 October 2016, #483 (p.11):

- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 7 October 2016 – ‘**Draft guidelines address regional variations, but there are worries over terminology, the needs of family members and implementation.**’ The death of a child is a comparatively rare event in the U.K. Even so, more than 3,000 infant and 2,000 children and young people age 1-19 years died in England and Wales in 2012. <https://goo.gl/HNI3sE>

Noted in Media Watch 6 June 2016, #465 (p.8):

- *ARCHIVES OF DISEASE IN CHILDHOOD*, 2016;101(Suppl):A305-A306. ‘**Palliative care services for children and young people: Realist review of the literature.**’ The delivery of palliative care (PC) services for children and young people (CYP) in the U.K. is inconsistent, despite the development of guidance, recommendations and service standards. <http://goo.gl/W6g29j>

## Funding models in palliative care: Lessons from international experience

*PALLIATIVE MEDICINE* | Online – 3 February 2017 – As palliative care (PC) integrates into mainstream health care provision, opportunities to develop funding mechanisms arise. However, little has been reported on what funding models exist or how we can learn from them. Initial literature scoping yielded limited evidence on the subject as national policy documents are difficult to identify, access and interpret. The authors undertook expert consultations to appraise national models of PC financing in England, Germany, Hungary, Republic of Ireland, New Zealand, The Netherlands, Norway, Poland, Spain, Sweden, Switzerland, the U.S. and Wales. These represent different levels of service development and a variety of funding mechanisms. Funding mechanisms reflect country-specific context and local variations in care provision. Patterns emerging include the following: 1) Provider payment is rarely linked to population need and often perpetuates existing inequitable patterns in service provision.; 2) Funding is frequently characterised as a mixed system of charitable, public and private payers; and, 3) The basis on which providers are paid for services rarely reflects individual care input or patient needs. Funding mechanisms need to be well understood and used with caution to ensure best practice and minimise perverse incentives. Before we can conduct cross-national comparisons of costs and impact of PC, we need to understand the funding and policy context for PC in each country of interest. <https://goo.gl/1BPVhy>

## Brain-computer interface-based communication in the completely locked-in state

*PLOS BIOLOGY* | Online – 31 January 2017 – Despite scientific and technological advances, communication has remained impossible for persons suffering from complete motor paralysis, but intact cognitive and emotional processing, a condition that is called completely locked-in state. Brain-computer interfaces based on neuro-electrical technology (like an electroencephalogram) have failed at providing patients in a completely locked-in state with means to communicate. The authors explored if a brain-computer interface based on functional near infrared spectroscopy (fNIRS) – which measures brain hemodynamic responses associated with neuronal activity – could overcome this barrier. Four patients suffering from advanced amyotrophic lateral sclerosis (ALS), two of them in permanent completely locked-in state and two entering the completely locked-in state without reliable means of communication, learned to answer personal questions with known answers and open questions requiring a “yes” or “no” by using frontocentral oxygenation changes measured with fNIRS. These results are, potentially, the first step towards abolition of completely locked-in states, at least for patients with ALS. <https://goo.gl/Y1ttrn>

Noted in Media Watch 23 June 2014, #363 (p.10):

- *BRAIN INJURY* | Online – 9 June 2014 – ‘**A European survey on attitudes towards pain and end-of-life issues in locked-in syndrome.**’ From the 3,332 respondents [to a close-ended survey] – 33% physicians, 18% other clinicians, 49% other professions; 47% religious – 90% agreed that patients with locked-in syndrome can feel pain. The majority (75%) disagreed with treatment withdrawal, but 56% did not wish to be kept alive if they imagined themselves in this condition. Religious and southern Europeans opposed to treatment withdrawal more often than non-religious and participants from the North. When the locked-in syndrome was compared to disorders of consciousness, more respondents endorsed that being in a chronic locked-in syndrome was worse than being in a vegetative state or minimally conscious state for patients (59%) than they thought for families. <https://goo.gl/jgyNx7>

## End-of-life care in Switzerland

### General practitioners’ attitudes towards essential competencies in end-of-life care: A cross-sectional survey

*PLOS ONE* | Online – 1 February 2017 – Identifying essential competencies in end-of-life care (EoLC), as well as general practitioners’ (GPs) confidence in these competencies, is essential to guide training and quality improvement efforts in this domain. Ninety-nine percent of GPs [i.e., survey respondents] considered the recognition and treatment of pain as important; 86% felt confident about it. Few GPs felt confident in cultural (16%), spiritual (38%) and legal end-of-life competencies such as responding to patients

Cont.

seeking assisted suicide (35%), although more than half of the respondents regarded these competencies as important. Most frequent reasons to refer terminally ill patients to a specialist were lack of time (30%), better training of specialists (23%), and EoLC being incompatible with other duties (19%). In multiple regression analyses, confidence in EoLC was positively associated with GPs' age, practice size, home visits, and palliative training. GPs considered non-somatic competencies (such as spiritual, cultural, ethical and legal aspects) nearly as important as pain and symptom control. Yet, few GPs felt confident in these non-somatic competencies. These findings should inform training and quality improvement efforts in this domain, in particular for younger, less experienced GPs. <https://goo.gl/zdU4n3>

Noted in Media Watch 12 September 2016, #479 (p.14):

- *PLOS ONE* | Online – 6 September 2016 – ‘**Health care utilisation and transitions between health care settings in the last 6 months of life in Switzerland.**’ In Switzerland, palliative care (PC) is not yet available for all patients in need and there are considerable regional variations. Some regions have a broader supply of PC centres, including mobile PC teams (i.e., the Western/French speaking part of Switzerland), whereas other regions (i.e., the Central part of Switzerland) hardly have any offering. According to the National Palliative Care Strategy 2013-2015, as little as four out of 26 cantons have hospices available. Further more, the financing of PC is neither uniformly nor conclusively regulated in Switzerland. <http://goo.gl/Jvm5hh>

Noted in Media Watch 18 July 2016, #471 (p.6):

- SWITZERLAND | Swissinfo.ch (Bern) – 11 July 2016 – ‘**Why is Switzerland behind in palliative care?**’ Switzerland has a short history of encouraging palliative care (PC), with more awareness of curative treatment, acute care and assisted suicide as end of life options. The need for PC – well-planned, multidisciplinary support for terminally ill patients and their families – will increase, given the ageing population. And so will the costs of this care. But these can be lowered if PC is properly planned, as is the case in countries like Australia and the U.K. <http://goo.gl/Szg97H>

**N.B.** Additional articles on end-of-life care in Switzerland are noted in this issue of Media Watch.

### **Online palliative care and oncology patient education resources through Google: Do they meet national health literacy recommendations?**

*PRACTICAL RADIATION ONCOLOGY* | Online – 27 January 2017 – The American Medical Association and National Institutes of Health recommend that patient education resources be written between the third and seventh grade reading levels. The authors assessed the readability levels of online palliative care (PC) patient education resources using ten readability algorithms widely accepted in the medical literature. In October 2016, ten terms pertaining to PC and oncology were individually searched for using the Google search engine, and the first ten articles written for the public for each term were downloaded for a total of 100 articles. The terms included: PC, hospice, advance directive, cancer pain management, treatment of metastatic disease, treatment of brain metastasis, treatment of bone metastasis, palliative radiation therapy, palliative chemotherapy, and end-of-life care. The authors determined the average reading level of the articles.... Most PC education articles readily available on Google are written above national health literacy recommendations. There is need for revision of these resources to allow patients and their families to derive the most benefit from these materials. <https://goo.gl/MX8pPP>

Noted in Media Watch 2 January 2017, #493 (p.8):

- *CANCERS* | Online – 13 December 2016 – ‘**Ensuring quality in online palliative care resources.**’ Clinicians, patients, community members, and decision makers have an unprecedented capacity to find online information about palliative care and end-of-life care. However, it is clear that not all individuals have the skills to be able to find and assess the quality of the resources they need. <https://goo.gl/c1RC98>

## End-of-life care in Germany

### Centenarians preparing for the end of life?

*ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE* | Online – 31 January 2017 – The population of centenarians has grown in Germany, but has yet hardly been considered in research on dying and death. Due to their very old age centenarians are especially intensively confronted with the challenge of the end of life. The aim of this study was to analyze how centenarians handle the existential challenge of the end of life and which aspects are especially significant for them. Conclusions drawn from this analysis were used to identify factors to improve the needs-based provision of care. In the categories “experience with dying and death” and “preparing for the end of life” it was shown to be significant that respondents often referred to the dying of others with respect to their worries and wishes at the end of their life. Additionally, the sub-categories “putting things in order,” “settling provision of care” and “having conversations” were shown to be highly relevant for the participants in the study. Decisions related to care in the process of dying, for example by advance directives, arrangements for inheritance and funeral as well as communication about dying and death, are central needs of centenarians when preparing for the end of life. There is sometimes considerable need for professional support and protection. <https://goo.gl/tlsZYf>

**N.B.** German language article.

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BC MEDICAL JOURNAL*, 2017;59(1):49-52. **‘Medical assistance in dying: Living with dignity until life naturally ends.’** Medical progress has allowed us to live longer with less disability. But because the culture of medicine identifies life prolongation as its premier goal, death is viewed as a failure rather than a natural completion of the life cycle. Identifying the tipping point where prolonging living becomes prolonging dying, stopping technology, and managing the dying process requires a skill set not emphasized in medical schools. Witnessing prolonged dying with poor symptom control has made people even more fearful of the dying process. And society has given over to medicine the entire care of the aging, disabled, and dependent, abandoning them to an isolated existence. It is not surprising that Canada now has a law permitting physician-assisted death. <https://goo.gl/NZ3R7f>
- *BC MEDICAL JOURNAL*, 2017;59(1):48,50. **‘Medical assistance in dying: Controlling the timing of one’s own death.’** We know from surveys ... that most Canadians (and medical leaders) would prefer to die at home in their beds surrounded by their friends and family. My own father repeatedly asked me to help him die in the last 2 years of his life. The truth of the matter is that the vast majority of Canadians die in institutions after extensive medical interventions frequently without any family members or loved ones present. Arguments have been made that if Canadians had universal access to palliative care (PC) that medically assistance in dying (MAID) would not be necessary. Although I and every person I know who is involved with the MAID movement is strongly in favor of universal and readily available PC, in the end all patients in PC will die, and it remains my view that it is the patient who should have control over the timing of his or her death – not a facility, an institution, or a doctor. <https://goo.gl/VuAWFk>
- *JOURNAL OF MEDICAL ETHICS* | Online – 30 January 2017 – **‘Is medically assisted death a special obligation?’** Several distinct arguments conclude that terminally ill patients have a right to a medically assisted death; two are especially influential: the autonomy argument and the non-harm argument. Both have proven convincing to many, but not to those who view the duty not to kill as an (almost) absolute constraint. Some philosophers see the source of such a constraint in general (deontological) moral principles, other in the nature of the medical profession. The author’s aim is not to add one further argument in favour of medically assisted death. Rather, he wants to shed light on a kind of reason that, to his mind, has not been previously highlighted or defended, and that might shake the principled conviction that doctors are never allowed to actively assist their patients to die. Specifically, the author’s purpose is to show that doctors (as members of the medical profession) have a special duty to provide medically assisted death to consenting terminally ill patients, because (and insofar as) they have been participants in the process leading to the situation in which a patient can reasonably ask to die. In some specific ways ... they are involved in the tragic fate of those patients and, therefore, are not morally allowed to straightforwardly refuse to assist them to die. <https://goo.gl/JzKuol>

## Worth Repeating

### **Distinguishing spiritual, psychological, and psychiatric issues in palliative care: Their overlap and differences**

*PROGRESS IN PALLIATIVE CARE*, 2012;20(2):79-85. The authors present a four-step assessment for determining which perspective and which clinician may best aid a patient: 1) Distinguish whether suffering is due to a normal syndrome of distress or to a psychiatric disorder; 2) Assess the potential efficacy of spiritual care, psychotherapy, or psychopharmacology for relieving distress of this type; 3) Determine probable effectiveness for spiritual care, psychotherapy, or psychopharmacology given limitations of clinician availability, clinicians' clinical competencies, and the treatment setting; and, 4) Learn whether the patient has a strong preference for a consultant with a secular (psychiatrist, psychotherapist) or religious (chaplain, clergy) professional identity. This assessment prioritizes patient preferences in its decision making, while evaluating the clinical problem, consultants' capabilities, and treatment setting so that recommendations hold promise for effectiveness. Spirituality, psychology, and psychiatry are each richly developed traditions of healing. The aim of care should be to provide the best from each towards reducing a patient's suffering. [Noted in Media Watch 30 July 2012, #264 (p.12)] <https://goo.gl/RVfA1u>

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3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

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

### Media Watch: Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/7jyMed>

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

Cont.

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): <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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