

## 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 'Still searching: A meta-synthesis of a good death from the bereaved family member perspective' (p.9), in *Behavioral Sciences*.

## Canada

### Ontario set to begin shifting home care responsibilities

ONTARIO | CBC News – 25 April 2017 – Ontario begins dissolving its 14 community care access centres (CCACs) ... but, critics insist the move won't cut red tape, free up money or improve home care for patients. Every year more than 700,000 people in Ontario count on the personal support workers, nurses and therapists who are funded by CCACs. But the CCACs have been the subject of damning audits, and last December the government passed its Patients First Act, which handed the responsibility of home care to the local health integration networks in each region. The Ministry of Health & Long Term Care claims the merger will streamline administration of the health care system and lead to better home care. But home care advocates aren't convinced. <https://goo.gl/bvwwYq>

### Ontario boosts respite support and training with \$20 million investment

ONTARIO | Global TV News – 25 April 2017 – The funding will cover about 1.2 million hours of respite services for caregivers so that they can schedule breaks for rest, family commitments or other priorities. A new Ontario Caregiver Tax Credit in 2017 will replace the current caregiver and infirm dependent tax credits. The province also announced additional education and training programs for unpaid caregivers on how to provide care to loved ones at home in ways that work for them, including online, in group settings, and in a variety of languages. <https://goo.gl/UL9HYE>

Noted in Media Watch 21 December 2015, #441 (p.1):

- ONTARIO | *The Globe & Mail* – 17 December 2015 – '**Ontario moves to scrap troubled health agencies, reorganize primary care.**' Ontario is moving to scrap the troubled agencies responsible for home care and is proposing changes to the way primary care is organized to make it easier for people to find family doctors and get an appointment when they are sick. The move, made public in a discussion paper,<sup>1</sup> comes as the Liberal government faces mounting pressure to make changes to home care following a string of scathing reports. <http://goo.gl/4xWhXc>

1. 'Patients First: A Proposal to Strengthen Patient-Centred Health Care in Ontario...', Ministry of Health & Long Term Care, Ontario Provincial Government, 17 December 2015. <http://goo.gl/XVoG03>

Cont.

Noted in Media Watch 6 June 2016, #465 (p.2):

- ONTARIO | Health Quality Ontario – 1 June 2016 – ‘**Connecting patients with home care and community services among biggest challenges for Ontario family doctors.**’ Ontario has one of the lowest reported percentages of family physicians (FPs) communicating with home care and community services compared to FPs in other parts of Canada as well as those in Australia, France, Germany, The Netherlands, New Zealand, Norway, Sweden, Switzerland, the U.K., and the U.S. A new report shows FPs are experiencing systemic barriers when coordinating care for their patients in home and community services.<sup>1</sup> <http://goo.gl/4Uo5qU>

1. ‘Connecting the Dots for Patients,’ Health Quality Ontario, June 2016. <http://goo.gl/kE0lh6>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE GLOBE & MAIL* | Online – 26 April 2017 – ‘**At least 970 people received an assisted death in Canada in 2016: Report.**’ At least 970 people in Canada received an assisted death last year, according to a new federal report that provides the first official snapshot of how medical aid in dying is playing out in hospitals and homes across the country. Assisted deaths accounted for about 0.6% of all deaths nationwide, says the Health Canada report.<sup>1</sup> Nearly half of all the assisted deaths – 463 – took place in Quebec, where a separate end-of-life law took effect on 10 December 2015, six months before the federal law kicked in. There were 507 medically assisted deaths in the rest of Canada between 17 June 17 and 31 December of last year, the report says. <https://goo.gl/VDzTb1>

1. ‘Interim update on medical assistance in dying in Canada 17 June to 31 December 2016,’ Government of Canada, April 2017. <https://goo.gl/SgQiEy>

### U.S.A.

#### Lawmakers may make changes to tough prescribing law

MAINE | Associated Press – 28 April 2017 – Lawmakers concerned about the plight of residents with chronic pain are considering softening a tough law that puts limits on how much opioid painkillers a doctor can prescribe. Maine has the nation’s strictest limit for opioid prescriptions, part of a sweeping law that aims to stop doctors from over-prescribing the painkillers. The law passed last year... By July, Maine doctors will not be allowed to prescribe more than 100 milligrams of opioid medication per day to most of their patients. The law has a broad exception for “palliative care” that the state says protects patients with chronic or acute pain. But Rockland attorney Patrick Mellor says he’s heard from 100 people across Maine who say their doctors have told them they don’t qualify for the exceptions. <https://goo.gl/78gldM>

Noted in Media Watch 20 March 2017, #504 (p.14):

- *REHABILITATION ONCOLOGY* | Online – 27 February 2017 – ‘**Opioid campaigns’ impact on advanced cancer and hospice and palliative care.**’ Recent national opioid campaigns may have significant, unintentional, and adverse consequences on the medical management of patients with advanced cancers or those receiving hospice and palliative care. New guidelines are likely to impose even tighter controls on opioids, further reducing accessibility to these drugs. <https://goo.gl/Qw3dYU>



#### Media Watch Online

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

## **Kaiser/*Economist* survey highlights Americans' views and experiences with end-of-life care, with comparisons to residents of Italy, Japan and Brazil**

**KAISER HEALTH NEWS** | Online – 27 April 2017 – Half of Americans – including nearly six in ten of those in fair or poor health – say people in the U.S. have too little control over their end-of-life medical decisions... The cross-country survey ... highlight Americans' experiences and opinions about aging and end-of-life care (EoLC) and how this compares with the views and experiences of residents of Italy, Japan and Brazil. A separate report [see sidebar] focuses on the views and experiences of people in the U.S. While most residents of Italy, Japan and Brazil say the government bears primary responsibility for caring for people's health and long-term care needs as they age, Americans are more evenly divided with almost equal shares saying government (42%) and individuals and families (44%) should be most responsible. Most Americans (62%) say the U.S. government is "not too prepared" or "not at all prepared" to deal with the aging population, while a third (35%) say it is "very" or "somewhat" prepared. Americans are more split on whether the health care system and families in the U.S. are prepared to deal with the aging population, with about half saying each is prepared and the other half saying they are not. About a quarter (27%) of Americans, including half (51%) of adults age 65 and over, say they have written down their wishes for EoLC; these shares are much higher than the shares reporting taking such steps in the other three countries. Among those who haven't, the most common reason for not doing so is that they haven't gotten around to it. <https://goo.gl/nhw1zr>

### **Views and experiences with end-of-life medical care in the U.S.**

In partnership with *The Economist*, the Kaiser Family Foundation conducted a cross-country survey of adults in the U.S., Italy, Japan, and Brazil about people's views and experiences related to aging and end-of-life medical care. These four countries are each at different stages of population aging, and have different cultural and institutional considerations when it comes to preparing and providing care for those near the end of life. This report gives an overview of the survey results for the U.S. <https://goo.gl/iCCwd3>



Scroll down to [International](#) and 'How to have a better death' and 'Mending mortality' (pp.5-6), in *The Economist*.

### **[Specialist Publications](#)**

'Family presence at first cardiopulmonary resuscitation and subsequent limitations on care in the medical intensive care unit' (p.8), in *American Journal of Critical Care*.

## **Widespread hype gives false hope to many cancer patients**

**KAISER HEALTH NEWS** | Online – 27 April 2017 – Patients and families are bombarded with the news that the country is winning the war against cancer. The news media hypes research results to attract readers. Drug companies promise "a chance to live longer" to boost sales. Hospitals woo paying customers with ads that appeal to patients' fears and hopes. "I'm starting to hear more and more that we are better than I think we really are," said Dr. Otis Brawley, chief medical officer at the American Cancer Society. "We're starting to believe our own bullshit." The consequences are real – and they can be deadly. Patients and their families have bought into treatments that either don't work, cost a fortune or cause life-threatening side effects. Although scientists have made important strides in recent years, and many early-stage cancers can now be cured, most of those with advanced cancer eventually die of their disease. For decades, researchers have rolled out new cancer therapies with great fanfare, announcing that science has at last found a key to ending one of the world's great plagues, said Dr. Vinay Prasad, an assistant professor of medicine at Oregon Health & Science University. When such efforts fail to live up to expectations, the cancer world simply moves on to the next big idea. Hying early scientific results ... can attract investors that allow researchers to continue their work. <https://goo.gl/ewWSXJ>

Cont.

### **Selected articles on advertising and newspaper coverage related to cancer research**

- *JAMA INTERNAL MEDICINE*, 2016;176(8):1068-1070. ‘**Cancer center advertising: Where hope meets hype.**’ In the U.S. Cancer centers advertise to reach patients and their families in a very competitive market. Patients often have dangerous cancers and face toxic treatments and the advertisements offer hope. But the hope can – and often does – morph into hype. The marketing of cancer services is growing. An essential question is how to ensure that advertisements do not take advantage of vulnerable patients. [Noted in Media Watch 8 August 2016, #474 (p.8)] <http://goo.gl/qBnh2s>
- *eCANCER* | Online – 29 January 2015 – ‘**How do medical journalists treat cancer-related issues?**’ All of the journalists surveyed experienced difficulties in reporting health issues. Significant concerns included quality of information, social impact, lack of technical knowledge, and difficulty in understanding technical terms. Physicians were the most trusted source of information about cancer. As medical knowledge is advancing rapidly, journalists may have increasing difficulty covering cancer-related issues. [Noted in Media Watch 2 February 2015, #395 (p.8)] <http://goo.gl/FH4WUk>
- *BRITISH MEDICAL JOURNAL* | Online – 10 December 2014 – ‘**The association between exaggerations in health related science news and academic press releases: Retrospective observational study.**’ 40% of press releases analyzed contained exaggerated advice, 33% contained exaggerated causal claims, and 36% contained exaggerated inference to humans from animal research. Improving the accuracy of academic press releases could represent a key opportunity for reducing misleading health related news. [Noted In Media Watch 22 December 2014, #389 (p.14)] <http://goo.gl/UNYYGy>

### **“Model” nursing home for paroled inmates to get federal funds**

CONNECTICUT | *The Hartford Courant* – 26 April 2017 – 60 West is the first correctional facility in the country to win approval from the Centers for Medicare & Medicaid Services for federal nursing home funding – a designation that has national significance ... because it’s a new option for cash-strapped states looking for ways to care for growing populations of older and sicker inmates. Ailing inmates who qualify for nursing home-level care and who the state deems are not public safety risks are referred to 60 West. Medicaid covers half the cost of their care, which will save the state about \$5 million annually. Caring for the growing population of elderly prisoners is difficult because “prison infirmaries were not designed to serve chronically ill people or people who need hospice care,” said Judith Dowd, director of health and human services for the state’s Office of Policy & Management. 60 West is not the first Connecticut innovation to address the aging prison population. The state is one of a few with a prison hospice program in which fellow inmates care for dying prisoners. <https://goo.gl/AOQpXm>

**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 (updated 4 April 2017) is posted on the Palliative Care Community Network website at: <http://goo.gl/ZpEJyQ>

### **Severe shortage of home health workers robs thousands of proper care**

*KAISER HEALTH NEWS* | Online – 26 April 2017 – Acute shortages of home health aides and nursing assistants are cropping up across the country, threatening care for people with serious disabilities and vulnerable older adults. In Minnesota and Wisconsin, nursing homes have denied admission to thousands of patients over the past year because they lack essential staff, according to local long-term care associations. In New York, patients living in rural areas have been injured, soiled themselves and gone without meals because paid caregivers aren’t available, according to testimony provided to the state Assembly’s health committee in February. In Illinois, the independence of people with severe developmental disabilities is being compromised, as agencies experience staff shortages of up to 30%, according to a court monitor overseeing a federal consent decree. The emerging crisis is driven by low wages – around \$10 an hour, mostly funded by state Medicaid programs – and a shrinking pool of workers willing to perform this physically and emotionally demanding work: helping people get in and out of bed, go to the bathroom, shower, eat, participate in activities, and often dealing with challenging behaviors. <https://goo.gl/Oknb03>

Cont.

Noted in Media Watch 13 February 2017, #499 (p.2):

- **FORBES** | Online – 7 February 2017 – ‘**Finding solutions to the growing caregiver crisis.**’ We need to create a social infrastructure that will help families manage their caregiving responsibilities. In addition to adopting family-friendly workplace policies – for example, guaranteed paid family leave – we need to ensure that growing numbers of family caregivers can supplement the care they provide with the services of professional home care aides who are compassionate, skilled and reliable. But finding these workers is becoming increasingly difficult. <https://goo.gl/35UVoC>

### **Hospice data looks at time spent with patients**

MISSOURI | News-Press Now (St. Joseph) – 23 April 2017 – The Centers for Medicare & Medicaid Services (CMS) ... has compiled national Medicare and Medicaid data on hospice providers to help both providers and consumers identify areas for improving care quality, ways to reduce program spending, and information for research across different studies and populations. The data includes time spent with hospice patients daily and also time spent with patients in their last seven days of life. Crossroads Hospice & Palliative Care ... evaluated 23 multi-state hospice organizations with a patient census of at least 500 people, according to the CMS data. They found that the overall time spent with each hospice patient by those organizations was an average of .635 hours, or about 40 minutes, per day. In the last seven days of life, that number decreased to .587 hours per day... <https://goo.gl/EjFln6>

## **International**

### **End-of-life care in the U.S., Italy, Japan, and Brazil**

#### **How to have a better death**

*THE ECONOMIST* | Online – 29 April 2017 – How, when and where death happens has changed over the past century. As late as 1990 half of deaths worldwide were caused by chronic diseases; in 2015 the share was two-thirds. Most deaths in rich countries follow years of uneven deterioration. Roughly two-thirds happen in a hospital or nursing home. They often come after a *crescendo* of desperate treatment. Nearly a third of Americans who die after 65 will have spent time in an ICU in their final three months of life. Almost a fifth undergo surgery in their last month. Such zealous intervention can be agonising for all concerned. Cancer patients who die in hospital typically experience more pain, stress and depression than similar patients who die in a hospice or at home. Their families are more likely to argue with doctors and each other, to suffer from post-traumatic stress disorder and to feel prolonged grief. Most important, these medicalised deaths do not seem to be what people want. Polls ... find that most people in good health hope that, when the time comes, they will die at home. And few, when asked about their hopes for their final days, say that their priority is to live as long as possible. Rather, they want to die free from pain, at peace, and surrounded by loved ones for whom they are not a burden. <https://goo.gl/kFeMqg>

#### **Extract from *The Economist* article**

More palliative care (PC) is needed. This neglected branch of medicine deals with the relief of pain and other symptoms, such as breathlessness, as well as counselling for the terminally ill. Until recently it was often dismissed as barely medicine at all: mere tea and sympathy when all hope has gone. Even in Britain, where the hospice movement began, access to PC is patchy. Recent studies have shown how wrongheaded that is. Providing it earlier in the course of advanced cancer alongside the usual treatments turns out not only to reduce suffering, but to prolong life, too.

#### **Specialist Publications**

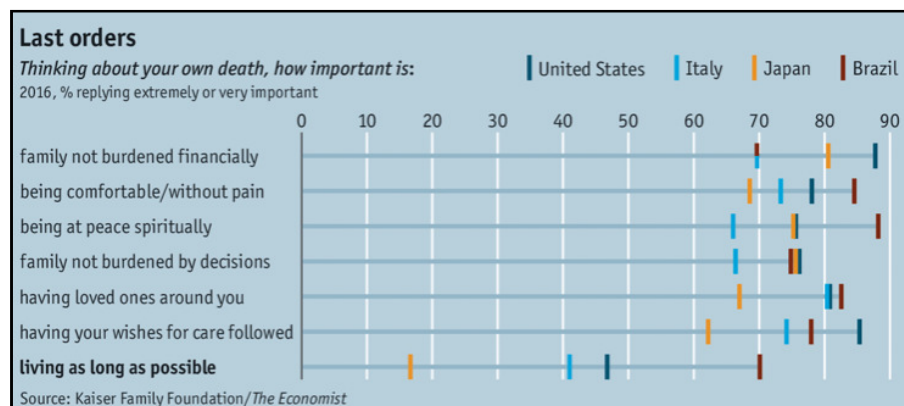
‘**Advance care planning, culture and religion: An environmental scan of Australian-based online resources**’ (p.8), in *Australian Health Review*.

‘**Shortage of children’s hospice nurses hitting care for U.K.’s sickest youngsters**’ (p.12), in *Nursing Times*.

Cont.

## Related

- *THE ECONOMIST* | Online – 29 April 2017 – ‘**Mending mortality.**’ The paradox of modern medicine is that people are living longer, and yet doing so with more disease. Death is rarely either quick or painless. Often it is traumatic. As the end nears, people tend to have goals that matter more than eking out every last second. But too few are asked what matters most to them. In the rich world most people die in a hospital or nursing home, often after pointless, aggressive treatment. Many die alone, confused and in pain. The distress is largely unnecessary. <https://goo.gl/3wh6HE>



‘What people most want in their final months.’ <https://goo.gl/9EeYzG>

- U.K. | *The Guardian* – 27 April 2017 – ‘**Thousands of cancer patients denied wish to die at home.**’ Tens of thousands of people with cancer are dying in hospital every year even though they would rather spend their final days at home or in a hospice. Although only 1% of cancer patients say they would prefer to die in hospital, 38% do, according to research by Macmillan Cancer Support,<sup>1</sup> equating to 62,000 people a year across the U.K. A lack of health services outside hospitals, such as district nurses, to support people in their homes in their last days has been cited as a key reason behind the discovery. <https://goo.gl/brBWfX>

1. ‘No regrets: How talking more openly about death could help people die well,’ Macmillan Cancer Support, April 2017. <https://goo.gl/9OJUZF>

## Elder care in England, Scotland & Wales

### **More than 2,000 elderly and ill people die while waiting for care at home: Worse cases saw patients waiting nine months for treatment**

U.K. (England, Scotland & Wales) | *The Daily Mail* – 24 April 2017 – Thousands of seriously ill patients are dying while waiting for basic care at home, figures reveal. In the past three years at least 2,037 adults died before care visits could be arranged in their homes. Many are likely to have had illnesses such as terminal cancer, dementia or motor neurone disease, which leave them housebound and dependent on help. In the worst cases, vulnerable patients were waiting for nine months for care to be arranged before they died. Many were forced to spend their final weeks in hospital as care that would have allowed them to die at home was never arranged. Others may have passed away at home having become increasingly reliant on family members for basic daily tasks. The delays have come

about because council social care budgets have been progressively slashed and cannot meet the needs of the increasingly dependent population. The details were obtained through Freedom of Information requests to councils in England, Scotland and Wales, and cover the period from 2014-2015 to 2016-2017. <https://goo.gl/0cdKt0>

### Specialist Publications

‘Palliative care clinicians’ knowledge of the law regarding the use of the Deprivation of Liberty Safeguards’ (p.10), in *BMJ Supportive & Palliative Care*.

Cont.

Noted in Media Watch 27 February 2017, #501 (p.4):

- U.K. (England, Northern Ireland, Scotland & Wales) | *The Daily Telegraph* – 22 February 2017 – ‘**Dying patients forced to spend last days in hospital amid funding wrangles.**’ Studies suggest that nine in 10 people would prefer to die in their own home or in a hospice. But a poll of almost 1,000 nurses found 94% were aware of cases where delays in funding and community provision of care meant dying patients were forced to remain in hospital. <https://goo.gl/jpqj6U>

Noted in Media Watch 23 May 2016, #463 (p.8):

- U.K. (England) | *The Northern Echo* (Buckinghamshire) – 19 May 2016 – ‘**Councils and GP groups “overlooking local end-of-life care needs.”**’ Hospice UK used the Freedom of Information Act to find out how well councils and National Health Service groups assessed the needs of dying people in their communities. More than a third of health and wellbeing boards, which are run by councils, do not consider the needs of dying people in their assessments of local needs. <http://goo.gl/1K8sDk>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (New South Wales) | Special Broadcasting Service – 24 April 2017 – ‘**Euthanasia case not so compelling: Expert.**’ Euthanasia is not the “panacea” to improving end-of-life care as the “media frenzy” suggests, says U.S. bioethicist Dr Ezekiel Emanuel. The case for legalising euthanasia and physician-assisted suicide (PAS) in Australia is less compelling when the scientific evidence is considered, says Dr. Emanuel. In an editorial for the *Medical Journal of Australia*,<sup>1</sup> Dr. Emanuel – chair of the Department of Medical Ethics & Health Policy at the University of Pennsylvania – writes euthanasia and PAS are not always quick and painless. The scientific evidence ... shows that pain is not the primary reason why people seek help in dying. Instead, psychological suffering is the driving factor, writes Dr. Emanuel. <https://goo.gl/jrBPIA>

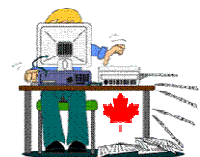
1. ‘Euthanasia and physician-assisted suicide: Focus on the data,’ *Medical Journal of Australia*, published online, accessed 24 April 2017. <https://goo.gl/YXvi8O>

**N.B.** See commentary on Dr. Ezekiel’s editorial, ‘Euthanasia debate: Is there such a thing as “good” suicide?’ *Medical Journal of Australia*, published online, accessed 24 April 2017. <https://goo.gl/7Y6lqn>

- CZECH REPUBLIC | *The Prague Daily Monitor* – 24 April 2017 – ‘**President, health minister reject euthanasia.**’ President Milos Zeman, Health Minister Miloslav Ludvik and his predecessor Svatopluk Nemecek ... reject the plan to make euthanasia legal in their [recent] talks at the presidential chateau... “We agreed with the president on a negative position on the possibility of euthanasia. There is palliative care, we can relieve pain. The introduction of possible killing is outside the rules,” Nemecek stated. Zeman was interested in the bill on dignified death that has been submitted by several MPs. The Chamber of Deputies is to discuss the bill at its present session. The government rejected the bill last year. Zeman has been promoting hospice care for the terminally ill and the dying. Hospice home care has been tested within a project financed by the VZP majority health insurer that is to be extended this year. <https://goo.gl/vPHETR>

### 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

### **Family presence at first cardiopulmonary resuscitation and subsequent limitations on care in the medical intensive care unit**

*AMERICAN JOURNAL OF CRITICAL CARE*, 2017;26(3):221-228. For unclear reasons, family-witnessed CPR in the intensive care unit (ICU) [of a tertiary academic medical center in Maryland, U.S.A.] was associated with a similar rate of subsequent CPR efforts and lower rates of return of spontaneous circulation (SC) and survival to hospital discharge. In 5 years, 323 patients underwent attempted CPR, of which 49 attempts (15.2%) were witnessed by family. In patients with return of SC, 40.9% of those whose first CPR was witnessed by family later had a do not attempt resuscitation order, which did not differ from patients whose first CPR was unwitnessed by family (31.8%). Family-witnessed CPR in the ICU was associated with significantly lower rates of return of SC (44.9%) than was family-unwitnessed CPR. Of all patients with a first CPR, 42 (13.0%) survived to hospital discharge. <https://goo.gl/LjR6vN>

Noted in Media Watch 7 February 2017, #501 (p.8):

- *JOURNAL OF MEDICAL ETHICS* | Online – 23 February 2017 – ‘**Family presence during resuscitation: Extending ethical norms from paediatrics to adults.**’ Currently, family presence is more commonly accepted in paediatric cardiopulmonary resuscitation (CPR) than adult CPR. Even though many guidelines are in favour of this practice and recognise potential benefits, healthcare professionals are hesitant to support adult family presence to the extent that paediatric family presence is supported. <https://goo.gl/N6Drzp>

**N.B.** Selected articles on relatives’ presence during cardiopulmonary resuscitation are noted in the 13 June 2016 issue of Media Watch (#466, p.12).

### **Advance care planning, culture and religion: An environmental scan of Australian-based online resources**

*AUSTRALIAN HEALTH REVIEW* | Online – 20 April 2017 – Health professionals and consumers frequently use the Internet to find information. Non-regulation has resulted in the proliferation of advance care planning (ACP) online resources. This paper is the first to use an environmental scanning methodology to identify Australian-based ACP websites and online informational booklets with cultural and religious information. Seven Australian-based ACP websites were identified with varying degrees of cultural and religious information. Seven ... were identified addressing culture or religion, namely of Aboriginal and Torres Strait Islander, and Italian communities. Twenty-one other online resources with cultural and religious information were identified, developed within the context of health and palliative care. There is no comprehensive Australian-based ACP website or informational booklet supporting ACP across several cultural and religious contexts. Considering Australia’s multicultural and multi-faith population, such a resource may be beneficial in increasing awareness and uptake of ACP. <https://goo.gl/MqYrnN>

### **Death cafés: Death doulas and family communication**

*BEHAVIORAL SCIENCES* | Online – 26 April 2017 – The Death Café (DC) is part of the “death positive movement” and, as such, is uniquely positioned to bring the dialogue about death and dying to the public. Participants in a DC typically have two different perspectives. Some participants have not experienced death in their family and friends’ circle and wish to converse with others about their beliefs on death and dying. Others are those who have experienced death somewhere in their circle of friends and families. One of goals of the DC facilitators is to help attendees reconcile their family narratives regarding death using the broader lens of the DC. This article discusses the role of the DC facilitators as the death doulas of family communication. <https://goo.gl/QVh1vF>

Cont.



Noted in Media Watch 2 November 2015, #434 (p.14):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 29 October 2015 – ‘**Death Café: What is it and what we can learn from it.**’ The article traces the history of the Death Café (DC) movement, explores some reasons why people take part in a DC gathering, and gives examples of what individuals think they might derive from their participation. The authors identify provisional lessons that can be drawn from DC gatherings and the DC movement itself. <https://goo.gl/0JRVRU>

#### Related

- *BEHAVIORAL SCIENCES* | Online – 20 April 2017 – ‘**Contradictions and promise for end-of-life communication among family and friends: Death over dinner conversations.**’ Researchers sought an answer to: “How do friend and family groups communicate about death and dying in death over dinner conversations? This study revealed that family and friend groups communicated similarly in that they talked about similar topics and used similar communication strategies to discuss these topics. Three major themes emerged: 1) Desire for a good death, which juxtaposed people’s perceptions of a “dreaded” death with those of a “desirable” death; 2) Tactics for coping, which consisted of the sub-themes of humour to diffuse tension or deflect discomfort, spiritual reassurance, and topic avoidance; and, 3) Topics that elicit fear or uncertainty, which consisted of the sub-themes of organ and whole-body donation, hospice and palliative care, wills and advance directives. <https://goo.gl/GT2hLS>
- *JOURNAL OF HEALTH COMMUNICATION* | Online – Accessed 27 April 2017 – ‘**The importance of intergenerational communication in advance care planning: Generational relationships among perceptions and beliefs.**’ Results of this study found significant relationships between grandparents and parents, as well as between parents and children for all variables except self-efficacy. Additionally, results of this study found indirect relationships between grandparents and their grandchildren for three variables. These findings underscore the need to treat advance care planning (ACP) as a family communication issue. Implications for how ACP should be approached in conversations with healthcare providers and within the family are discussed. <https://goo.gl/Pqu1K0>

#### Still searching: A meta-synthesis of a good death from the bereaved family member perspective

*BEHAVIORAL SCIENCES* | Online – 25 April 2017 – The authors argue that the meta-synthesis contributes to ongoing scholarly research and conversations related to end of life (EoL) and a good death in three ways. First, they narrowed the focus specifically to the perspective of the family members. Second, they expanded the database search for articles from the previous review to be more inclusive of published articles and obtain a more comprehensive view of the literature. Finally, the authors propose a conceptual model in order to help healthcare participants have more positive EoL experiences. They argue that the main contribution of the model is the ability to identify moments throughout the interaction where family members can be present to the EoL process. Recommendations for healthcare participants, including patients, family members and clinical care providers are offered to improve the quality of experience throughout the EoL process... <https://goo.gl/4XbYBq>

Noted in Media Watch 1 February 2016, #447 (p.6):

- *AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 22 January 2016 – ‘**Defining a good death (successful dying): Literature review and a call for research and public dialogue.**’ There is little agreement about what constitutes good death or successful dying. The definitions found were categorized into core themes and sub-themes and the frequency of each theme was determined by stakeholder (patients, family, health care providers perspectives). While there was agreement among stakeholders in the importance of many aspects of dying well, the presence of discrepancies in certain areas suggests a need for research on the impact of divergent perspectives on end-of-life care. Dialogues among the stakeholders for each individual must occur to ensure a good death from the most critical viewpoint – the patient’s. <http://goo.gl/u7GyUy>

**N.B.** Selected articles on defining a “good death” are noted in this issue of Media Watch.

Cont.

## Related

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 26 April 2017 – ‘**REMAP: A framework for goals-of-care conversations.**’ Conversations regarding goals-of-care with patients who have advanced cancer still occur too late, and oncologists say they lack the training to have these conversations effectively. Experts recommend a number of strategies when having these discussions, including discussing prognosis, responding to patient emotion, exploring values, and often making a recommendation for medical treatments that fit those values. <https://goo.gl/P7KJbw>

### **Palliative care for people with dementia in the terminal phase: A mixed-methods qualitative study to inform service development**

*BMC PALLIATIVE CARE* | Online – 28 April 2017 – The European Association for Palliative Care domain of “avoiding overly aggressive, burdensome, or futile treatment” was regarded of particular relevance in the terminal phase, along with a number of recommendations that refer to providing of comfort.<sup>1</sup> Families [i.e., family members interviewed] preferred continuity in care and living arrangements. Despite a recognition that this was a time when they had complex support needs, they found it difficult to accept involvement of a large team of unfamiliar (professional) caregivers. Mostly, terminal care was preferred at the place of residence. The expert interviews identified preferred, successful models in which a representative of a well-trained team has the time, authority and necessary expertise to provide care and education of staff and family to where people are and which ensure continuity of relationships with and around the patient. A mobile team that specializes in palliative care in dementia and supports professional and family caregivers is a promising model. Compared to transfer to a hospice in the last weeks or days, it has the potential to address the priorities of families and patients for continuity of care, relationships and specialist expertise. <https://goo.gl/l5C3bz>

1. ‘White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,’ *Palliative Medicine*, 2014;28(3):197-209. [Noted in Media Watch 8 July 2013, #313 (p.10)] <https://goo.gl/LoFDWE>

### **End-of-life care in England & Wales**

#### **Palliative care clinicians' knowledge of the law regarding the use of the Deprivation of Liberty Safeguards**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 24 April 2017 – There were 47 responses [to a regional postal survey of palliative care (PC) clinicians working in hospices in the East of England] from 14 different organisations; a response rate of 68%. Respondents included consultants, specialty and associate specialists, registrars, nurses and social workers. Higher self-reported confidence and training in the use of Deprivation of Liberty Safeguards (DoLS) was associated with higher factual knowledge. Consultants had the highest level of knowledge, training and experience. Doctors of other grades, nurses and social workers recorded less knowledge and experience and scored lower in the knowledge sections. The free-text comments revealed difficulty applying the safeguards in practice, particularly among the consultant responses, based around several themes: insufficient guidance on how to use the Safeguards, process after death, uncertainty as to relevance to PC and delays in assessments. <https://goo.gl/ND8MeM>

#### **Deprivation of Liberty Safeguards**

The Deprivation of Liberty Safeguards (DoLS), which apply only in England and Wales, are an amendment to the Mental Capacity Act 2005. The DoLS under the Act allows restraint and restrictions that amount to a deprivation of liberty to be used in hospitals and care homes – but only if they are in a person’s best interests.

- **N.B.** A recent Law Commission report, ‘Mental Capacity and Deprivation of Liberty,’ proposed a separate scheme regarding deprivation and liberty safeguards that would apply in general hospitals and palliative care and deliver safeguards in cases where a patient required (or there was a real risk the patient would require) care or treatment in his or her best interests that amounted to a deprivation of liberty, but the patient lacked capacity to consent to such care or treatment. **BRA** [Noted in Media Watch 20 March 2017, #504 (p.5)] <https://goo.gl/l2fGVD>

## Hospice or community network? Choices in end-of-life care in Jamaica

*INTERNATIONAL JOURNAL OF EVIDENCE-BASED HEALTHCARE* | Online – 26 April 2017 – National and international healthcare agencies and organizations typically attribute slow or haphazard growth in hospice and palliative care (PC) in developing countries to various resource constraints. This study provides evidence of the substantial and widening gap between policy advocacy and individual decision-making concerning end-of-life care (EoLC). It does so by establishing the incentives and risks that underlie choices of patients and providers against the relative scarcity of hospices in these countries. Jamaica offers an illustrative case. It shares the socioeconomic conditions and isolated provision of hospice and EoLC that remain prevalent in many developing countries. Financial and infrastructural challenges hamper hospice expansion and integration into formal healthcare systems in developing countries. However, other equally vital considerations are too often neglected. These include high transaction costs in decision-making, which account for limited hospice accessibility, affordability, and efficiency, particularly to underserved populations. Risk and payoff calculations by patients and their families as well as hospices and their providers lead to two strategic options in maximizing hospice value and/or minimizing transaction costs in EoLC. <https://goo.gl/BGzng1>

### End-of-life care in Australia

## How different administrative databases change the size of a potential palliative care population

*INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE* | Online – 18 April 2017 – Population-based studies in palliative care (PC) have used a range of administrative databases including death certificate data and linked hospital admissions data to identify people who received or could have benefited from PC. The authors conducted a study using linked hospital admissions and mortality data from the Western Australian Data Linkage System to evaluate how the size and distribution of the potential PC populations varied according to the data sources, whether linked data were used and how inclusion criteria were applied. Their cohort consisted of 23,852 people aged 20 years and over who died in Western Australia between 1 January 2009 and 31 December 2010 after excluding those whose deaths related to pregnancy or trauma. The number, proportion and characteristics of people who died from one or more of 10 medical conditions considered amenable to PC were identified using different information sources. Of the 23,852 people who died, a total of 10,445 (43%) people had a condition

potentially amenable to PC recorded as the underlying cause of death on their death certificate. This increased to 15,064 (63%) people when including one of these conditions listed anywhere on their death certificate. When hospital admission records from the last year of life and death records were used to identify people who might potentially have benefited from PC, there were 17,384 (73%) people identified with at least one of these conditions. <https://goo.gl/TS7g09>

### **Extract from *International Journal of Population Data Science* article**

The use of different data sources to identify conditions that might benefit from palliative care will result in differing frequency of conditions and age and sex distribution of the population. This is a result of many people having multiple conditions and the method in which these are recorded in different data sources. It is important to be aware of the characteristics of the individual data sources when the data are used for health service planning.

Noted in Media Watch 3 October 2016, #482 (p.15):

- *PALLIATIVE MEDICINE* | Online – 28 September 2016 – ‘**Estimating the need for palliative care at the population level: A cross-national study in 12 countries.**’ To implement the appropriate services and develop adequate interventions detailed estimates of the needs for palliative care (PC) are needed. The proportion of individuals who died from diseases that indicate PC needs at the end of life ranged from 38-74%. The authors found important cross-country variation. <https://goo.gl/DpLJ9O>

Cont.

## Related

- *PALLIATIVE MEDICINE* | Online – 28 April 2017 – ‘**Using intuition or a formal palliative care needs assessment screening process in general practice to predict death within 12 months: A randomised controlled trial.**’ Screening tool was better at predicting actual death than intuition, but with a higher false positive rate. Both were similarly effective at screening the whole cohort for death. Screening for possible death is not the best option for initiating end-of-life planning: recognising increased burden of illness might be a better trigger. <https://goo.gl/xtSHuo>

## End-of-life care in Scotland

### **Effect of sampling period on the numbers of children and young people with a life-limiting condition in stable, unstable, deteriorating and dying stages**

*INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE* | Online – 13 April 2017 – A national cohort of 20,436 children and young people (CYP) with a life-limiting condition ... was identified from linked routinely collected healthcare data. Over 2,200 were unstable, deteriorating or dying in each year. In 2010-2011, most severe stage of condition was stable for 10,678 (83%), unstable for 1,816 (14%), deteriorating for 253 (2%), and dying for 183 (1%). Over shorter periods the stable fraction increased... However, the yearly figures for instability were lower (e.g., 1,816 were unstable as most severe stage in 2010-2011) than the sum of monthly totals (summing monthly figures for 2010-2011, 4,367 were unstable). The differences dependent on the sampling period show the degree of variability in the group of patients experiencing instability, with different individuals having periods of instability at different points in the year, but also some individuals having multiple episodes of instability. In informing healthcare provision and planning it is important to understand these differences in numbers in each category across different time periods. <https://goo.gl/4spnQ2>

## Related

- *NURSING TIMES* | Online – 27 April 2017 – ‘**Shortage of children’s hospice nurses hitting care for U.K.’s sickest youngsters.**’ A nursing shortfall means that children’s hospices are being increasingly forced to cut back on the vital palliative care they can offer to families, according to a charity.<sup>1</sup> Its survey of children’s hospices shows the nurse vacancy rate in such settings is higher than National Health Service and has been growing since 2015. <https://goo.gl/n97MQY>

1. ‘The state of the UK children’s hospice nursing workforce: A report on the demand and supply of nurses to children’s hospice,’ Together for Short Lives, April 2017. <https://goo.gl/GCMmgx>

### **A qualitative study of community nurses’ decision-making around the anticipatory prescribing of end-of-life medications**

*JOURNAL OF ADVANCE NURSING* | Online – 19 April 2017 – Nurses believe they advocate for dying person and their families’ needs and lead negotiations with general practitioners (GPs) for medications to go into the home. This nurse-led care alters the traditional boundaries of the GPs-nurse professional relationship. Three themes were identified: 1) Drugs as a safety net (anticipatory medications give nurses a sense of control in last-days-of-life symptom management); 2) Reading the situation (the nurse judges when to introduce conversations around anticipatory medications, balancing the need for discussion with the dying person and their family’s likely response); and, 3) Playing the game (the nurse owns the decision to initiate anticipatory medication prescribing and negotiates with the GP). <https://goo.gl/pV9bHF>

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Noted in Media Watch 7 November 2016, #486 (p.12):

- *PRIMARY HEALTH CARE* | Online – 27 October 2016 – ‘**Anticipatory prescribing for end-of-life care: A survey of community nurses in England.**’ Respondents reported taking prominent roles throughout the anticipatory prescribing process and principal responsibility for administering and monitoring medications. Many recounted good working relationships with GPs. However, some reported being challenged by GPs who were reluctant to prescribe medication... <https://goo.gl/D5b0N3>

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

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

### **Studies of physician-patient communication with older patients: How often is hearing loss considered? A systematic literature review**

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 24 April 2017 – Hearing loss is prevalent in the geriatric population: one-quarter of adults aged 60-69 and 80% of adults aged 80 years and older have bilateral disabling loss. Only about one in five adults with hearing loss wears a hearing aid, leaving many vulnerable to poor communication with healthcare providers. Three studies examined or reported on an association between hearing loss and the quality of physician-patient communication. One included an intervention to temporarily mitigate hearing loss to improve communication. Less than one-quarter of studies of physician-elderly patient communication even mention that hearing loss may affect communication. Methodologically, this means that many studies may have omitted an important potential confounder. Perhaps more importantly, research in this field has largely overlooked a highly prevalent, important, and remediable influence on the quality of communication. <https://goo.gl/5NZoJM>

Noted in Media Watch 13 February 2017, #499 (p.10):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(1):97-103. ‘**Assessment and intervention for patients with hearing loss in hospice.**’ Hearing loss can interfere with critical communication exchanges that occur during admissions to hospice as well as during home or inpatient care. Three case scenarios are provided to illustrate these points. A comprehensive plan of options from screening to specific interventions is summarized. <https://goo.gl/Ido27B>

**N.B.** Selected articles on hearing loss in the context of end-of-life care are noted in the 4 April 2016 issue of Media Watch (#456, p.13).

### **Shouldn't dead be dead?: The search for a uniform definition of death**

*JOURNAL OF LAW, MEDICINE & ETHICS* | Online – 20 April 2017 – In 1968, the definition of death in the U.S. was expanded to include not just death by cardiopulmonary criteria, but also death by neurologic criteria. The authors explore the way the definition has been modified by the medical and legal communities over the past 50 years and address the medical, legal and ethical controversies associated with the definition at present... <https://goo.gl/tsF1oI>

Noted in Media Watch 23 January 2017, #496 (p.11):

- *NEUROCRITICAL CARE* | Online – 11 January 2017 – ‘**Physician power to declare death by neurologic criteria threatened.**’ Three recent lawsuits in the U.S. that address declaration of brain death (BD) garnered significant media attention and threaten to limit physician power to declare BD. These cases ... threaten to: 1) Limit physicians’ power to determine death; 2) Incite families to seek injunctions to continue organ support after BD; and, 3) Force hospitals to dispense valuable resources to dead patients in lieu of patients with repairable illnesses or injuries. <https://goo.gl/G1QutD>

## Comparing the palliative care needs of those with cancer to those with common non-cancer serious illness

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 April 2017 – Historically, palliative care (PC) has been focused on those with cancer. While these ties persist, PC is rapidly integrating into the care of patients with common, non-cancer serious illnesses. Despite this, the bulk of literature informing PC practices stems from the care of cancer patients. The authors conducted a cross-sectional, retrospective analysis of the characteristics and symptoms of patient's with renal disease (ESRD), heart failure (HF), chronic obstructive pulmonary disease (COPD), and cancer at time of first specialty PC referral. Patients with COPD, ESRD and HF were less functional and more likely to be hospitalized at time of referral to PC than cancer patients. These findings may be reflective of the slower and more varied trajectory of non-cancer serious illness. One aim of PC for those with non-cancer severe illness should be directed towards improving and assisting with functionality and decreasing frequency of hospital admissions. These interventions could take place in the PC office, but could also be integrated into hospital discharge plans. <https://goo.gl/lIXHNw>

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

- *PLOS ONE* | Online – 25 January 2016 – '**Dignity and distress towards the end of life across four non-cancer populations.**' Study subjects included patients with advanced amyotrophic lateral sclerosis (ALS), chronic obstructive pulmonary disease (COPD), end stage renal disease (ESRD); and, institutionalized alert frail elderly. While moderate to severe loss of sense of dignity did not differ significantly across the four study populations, the number of Patient Dignity Inventory items reported as problematic was significantly different. Each of the study populations also revealed unique and distinct patterns of physical, psychological and existential distress. <http://goo.gl/szA5HL>

Noted in Media Watch 19 May 2014, #358 (p.10):

- *PALLIATIVE MEDICINE* | Online – 12 May 2014 – '**The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: A systematic review of views from patients, carers and health-care professionals.**' Patients and carers expect primary care physicians to provide compassionate care, have appropriate knowledge, and play central roles in providing care. The roles of professionals are unclear to patients, carers and professionals themselves. Uncertainty of illness trajectory and lack of collaboration between health-care professionals were identified as barriers to effective care. <https://goo.gl/396Ssz>

## Compassion fatigue and compassion satisfaction in hospice social work

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 20 April 2017 – As part of the interprofessional team of hospice caregivers, social workers are exposed to multiple stressors, both in their work with dying patients and their families, and in functioning as professionals within rapidly changing health care organizations. Ongoing exposure to such stressors prompts concern about the emotional and psychological effect working with people who are dying may have on those who do it. Further, an understanding is needed regarding how hospice social workers interpret the costs and benefits of their work and how they cope with the dying and loss that pervade their everyday work lives. This study explored the prevalence of compassion fatigue (CF) among hospice social workers and considered compassion satisfaction (CS) as a means to mitigate CF. Results [of an online survey] suggested that CF is indeed a concern among hospice social workers. In addition, CF and CS were found to be negatively correlated and suggested that CS may act as a protective mechanism against CF. <https://goo.gl/ymFNpS>

## Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

## Potential for low-value palliative care of patients with recurrent head and neck cancer

*THE LANCET ONCOLOGY* | Online – 26 April 2017 – Curative treatment for patients with advanced head and neck cancer can be associated with many side-effects, and many patients suffer from persistent treatment-related side-effects. Patients with recurrent cancer bear the burden of these effects along with additional symptoms attributed to the recurrent tumour. To better understand the benefits and burden of palliative treatments for patients with recurrent head and neck cancer, the authors reviewed the evidence on commonly used palliative treatments and their effect on quality of life. When used for palliative care purposes, chemotherapy and radiotherapy have limited effectiveness in improving quality of life. Moreover, if these treatments are not congruent with a patient's end-of-life goals, they could constitute low-value care. The authors recommend that patients with advanced and recurrent cancer should be offered early, comprehensive palliative and supportive services to maximise benefit. The principles of beneficence and respect for patients in the context of shared decision making must prevail if the trust of this vulnerable patient population is to be honoured. <https://goo.gl/gdvJJY>

Noted in Media Watch 12 October 2015, #431 (p.16):

- *JAMA OTOLARYNGOLOGY HEAD & NECK SURGERY* | Online – 8 October 2015 – ‘**The cost of hospice services in terminally ill patients with head and neck cancer.**’ Patients who received hospice care had \$7,035 lower costs in the last month of life for oral cavity cancer and \$7,430 lower costs in the last month of life for pharyngeal cancer. These cost savings were greater in the last month of life when patients enrolled in hospice more than 30 days before death. <https://goo.gl/p5FHET>

Noted in Media Watch 21 May 2012, #254 (p.5):

- *HEALTH COMMUNICATIONS* | Online – 10 May 2012 – ‘**Beyond good intentions and patient perceptions: Competing definitions of effective communication in head and neck cancer care at the end of life.**’ Oncologists viewed giving prognostic information as a process rather than a singular event and preferred answering patients' questions as opposed to guiding the discussion. Subtle disconnects in communication suggesting patients' and health care providers' information needs are not being met. <https://goo.gl/9idJ5Q>

## Spiritual care in the intensive care unit: An integral part of daily intensive care

*THE NETHERLANDS JOURNAL OF CRITICAL CARE*, 2017;25(2):62-65. High-tech components such as drug therapy, mechanical ventilation, renal replacement therapy and many kinds of monitoring characterise day-to-day care in the intensive care unit (ICU). They yield the impression of safety and control, to reassure patients' uncertainties, pain, bereavement and agony. Naturally, doctors and nurses give priority to maintenance of the clinical aspects. However, the primary focus on the treatment of clinical symptoms may impede the understanding of the spiritual needs of patients. A life-threatening disease may lead to an existential crisis with patients and their relatives. Consequently, questions related to their beliefs and worldview arise. Spiritual caregivers can play a complementary role in meeting spiritual needs within whole patient care. However, structured and protocolled spiritual care is scarce. In this review the authors highlight a more or less unexplored area of ICU patient care and intend to encourage spiritual caregivers to get increasingly involved in routine ICU care. <https://goo.gl/D59FJO>

Noted in Media Watch 13 February 2017, #499 (p.10):

- *DIMENSIONS OF CRITICAL CARE NURSING*, 2017;36(2):110-115. ‘**Creating a sacred space in the intensive care unit at the end of life.**’ Critically ill patients and their families identify significant unmet spiritual, environmental, and communication needs. Although the Society of Critical Care Medicine recommends that the spiritual needs of critically ill patients be addressed by the health care team and be incorporated in patients' plans of care, spiritual concerns are infrequently addressed during goals-of-care discussions. <https://goo.gl/LRAJ5L>

Cont.

Noted in Media Watch 22 August 2016, #476 (p.8):

- *AMERICAN JOURNAL OF RESPIRATORY CRITICAL CARE MEDICINE* | Online – 15 August 2016 – **‘Experiences and expressions of spirituality at the end of life in the intensive care unit.’** The austere setting of the intensive care unit (ICU) can suppress expressions of spirituality. Participants [in this study] characterize dying as a spiritual event. Spirituality is an integral part of the life narrative of the patient before, during, and after death. Experiences and expressions of spirituality for patients, families and clinicians during end-of-life care in the ICU are supported by eliciting and implementing wishes in several ways. <http://goo.gl/oUD9IL>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AMERICAN JOURNAL OF PUBLIC HEALTH* | Online – 20 April 2017 – **‘How California prepared for implementation of physician-assisted death: A Primer.’** To help providers and health care facilities in California prepare to provide optimal care to patients who inquire about physician-assisted death, the authors ... convened a conference of 112 stakeholders in December 2015, and in this article present their recommendations. Themes of recommendations ... included: 1) Institutions should develop and revise physician-assisted death policies; 2) Legal physician-assisted death will have implications for California’s culturally and socioeconomically diverse population, and for patients from vulnerable groups; 3) Conscientious objection and moral distress for health care providers must be considered; and, 4) Palliative care is essential to the response to the law. <https://goo.gl/eROO7D>
- *ASIA PACIFIC JOURNAL OF HEALTH LAW & ETHICS* | Online – Accessed 29 April 2017 – **‘How to die in Colombia: A constitutional dilemma.’** In 1997, Colombia’s Constitutional Court decriminalized the medical practice of euthanasia in patients with serious and incurable diseases. Decision C-239 became one of the most radical advancements on the right to die debates in the world. At the time, European countries who have led this discussion, such as The Netherlands, hadn’t legalized and incorporated the right to die into their own legal systems. The author analyzes the reasoning behind Decision C-239 and the long pathway to its implementation in the first Latin American country to legalize euthanasia. He also examines other constitutional actions presented by terminal patients in defense of their right to die. The objective of this article is to provide routes of constitutional strategic litigation for advocates in other countries by building upon Colombia’s experience, and to study the role of the Constitutional Court in shaping ethical debates such as euthanasia. <https://goo.gl/1xQFEj>
- *CLINICAL ETHICS* | Online – 19 April 2017 – **‘Is healthcare providers’ value-neutrality depending on how controversial a medical intervention is? Analysis of 10 more or less controversial interventions.’** Studies among Swedish physicians have indicated the proportion of those whose personal values influence decision-making ... vary depending on the framing and the nature of the issue [including medically assisted death]. This study indicates that the proportions of value-neutral participants decrease the more controversial an issue is, and vice versa. In some cases, however, framing effects may potentiate or obscure this association. As a bold hypothesis, the authors suggest the proportion of value-neutral or value-influenced might indicate how controversial an issue is. <https://goo.gl/T2UEni>
- *JOURNAL OF COMMUNITY & SUPPORTIVE ONCOLOGY*, 2017;15(1):1-3. **‘End-of-life options and the legal pathways to physician aid in dying.’** By early 2017, roughly 18% of all U.S. citizens will reside in a state with a legal pathway to physician aid in dying via lethal prescription. When the End of Life Options Act went into effect in California in June 2016, it became the fourth state with laws allowing physician aid in dying (PAD). Oregon (1997), Washington (2009), and Vermont (2009) had preceded it, and Montana (2009) operates similarly as a result of a Supreme Court decision there. However, California’s law also legalized PAD in a state that is much larger and more socioeconomically diverse than the other four states – with its 39 million residents, California more than triples the number of Americans who live in PAD legal states. Together, these 5 states represent 16% of the entire U.S. population (roughly 321 million according to the 2015 Census). Most recently, in December 2016, they were joined by Colorado, adding a state population of 5.5 million. <https://goo.gl/tXx7Xd>

Cont.



- *PALATIATIA*, 2017;10(2). 'Palliative care instead of assisted suicide and euthanasia? About questionable needs of life-shortening behaviour.' Euthanasia and assisted suicide are discussed more and more in palliative care (PC) because of fear for suffering. This raises questions about the PC options. Is PC sufficient for patients for pain relief or symptom control in the final phase of life? Palliative sedation can be used as a method of choice indicated if other measures of symptom control do not work or are not desired. Is assisted suicide also used in PC? The authors asked medical specialists in 49 specialized outpatient PC teams in Germany about their opinions and practice concerning euthanasia and assisted suicide. They conclude that ... assisted suicide and euthanasia are not necessary in PC patients with physical suffering because alternative options for alleviation of suffering are present. This study indicates that effective suicide prevention at the end of life is possible when PC is provided by specialized outpatient PC teams. <https://goo.gl/Z5NGyK>

## Worth Repeating

### **Gently into the good night: Toward a compassionate response to end-stage illness**

*TEMPLE POLITICAL & CIVIL RIGHTS LAW REVIEW*, 2013;22(2):475-492. End-of-life decision making by health care providers must respect individual patient values. Indeed, these values must always be viewed as the baseline for developing and pursuing patient-centered palliative care (PC) for those with terminal illness. Co-ordinate with this fundamental bioethics principle is that of beneficence or, in other words, respect for conduct which benefits the dying patient by alleviating end-stage suffering – be it physical or existential. Compassion, charity, agape and/or just common sense, should be a part of setting normative standards and of legislative and judicial responses to the task of managing death. Aided by the principles of medical futility, PC protocols, greater acceptance of a patient's right to refuse treatment, and a spirit of basic humaneness, an ethic of adjusted care that seeks to secure dignity during the dying process without unreasonable interference by the state should be validated. <https://goo.gl/iiukzl>

### 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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### 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/j46LpJ>

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

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

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

### **Asia**

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

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

### **Canada**

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <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/5d1l9K>

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

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