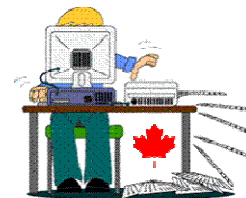


## Media Watch...

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 'Palliative care in critical care settings: A systematic review of communication-based competencies essential for patient and family satisfaction' (p.8), in *American Journal of Hospice & Palliative Medicine*.

## Canada

### First step to improving palliative care: Change its name

*THE TORONTO STAR* | Online – 30 August 2016 - We are doing a disservice to our patients and their families – and I would argue that much of that disservice can be linked to the cloud of darkness, misunderstanding, and stigma that surrounds the name palliative care (PC) itself. Perhaps it is my naivety as a student, but I can't help but feel that it's time for a change. PC is broken. The goal is to support people as they approach one of the most challenging times they will ever face – emotionally, intellectually, and financially. The goal is to support – so why not call it supportive care? Some major centres have even played with this idea. The MD Anderson Cancer Center in Texas, a global leader in oncology and PC, surveyed physicians to ask if they thought a name change to supportive care could impact referrals. Overall, physicians preferred the name supportive care, and expressed they were more likely to refer patients to a service with that name. These were not the only interesting results – physicians also found that

the term “palliative” more frequently causes distress and hopelessness in patients and families. They then trialed the name change at their own palliative – whoops, supportive – care centre, and actually saw an increase in referrals over a nine-month period. The research and sample size are small, but what does exist suggests that a name change could have a real impact on perceptions, and more importantly, patient access to PC. <http://goo.gl/rAfGHN>



Law Commission of Ontario  
Commission du droit de l'Ontario

### Improving the Last Stages of Life

The Commission recently released three new research papers in this series: <http://goo.gl/anPjz>

**N.B.** The author does not identify the specific study conducted at the MD Anderson Cancer Center. One conducted at the Center's Department of Palliative Medicine was published in *Supportive Care in Cancer*, 31 August 2012, 'Concepts and definitions for “supportive care,” “best supportive care,” “palliative care,” and “hospice care” in the published literature, dictionaries, and textbooks,' [Noted in Media Watch 3 September 2012, #269 (p.7)] <http://goo.gl/7MHmPc>

Cont.

### Selected articles on terminology used in defining end-of-life care

- *CANADIAN MEDICAL ASSOCIATION JOURNAL* | Online – 18 April 2016 – ‘**Perceptions of palliative care among patients with advanced cancer and their caregivers.**’ There is a strong stigma attached to palliative care (PC), which may persist even after positive experiences with an early PC intervention. Education of the public, patients and health care providers is paramount if early integration of PC is to be successful. [Noted in Media Watch 25 April 2016, #459 (p.2)] <http://goo.gl/3V0xPd>
- *PALLIATIVE MEDICINE* | Online – 29 January 2015 – ‘**What’s in a name? A qualitative exploration of what is understood by “palliative care” in the emergency department.**’ There are entrenched contradictions and tensions surrounding the term “palliative care.” Confronting these is likely to require more than re-branding and will promote better care for this vulnerable patient group. [Noted in Media Watch 9 February 2015, #396 (p.11)] <http://goo.gl/EAAIAI>
- *THE ONCOLOGY REPORT* | Online – 10 April 2013 – ‘**Is the moniker “palliative care” too loaded?**’ A survey of 169 patients with advanced cancer found those randomized to hear the term “supportive care” instead of “palliative care” rated their understanding, overall impressions and future perceived need for those services significantly higher. [Noted in Media Watch 15 April 2013, #301 (pp.14-15)] <http://goo.gl/9zERC0>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 2 September 2016 – ‘**More than 100 Canadians have opted for assisted death since law passed.**’ Doctors and nurse practitioners have helped hasten the deaths of more than 100 Canadians since the federal law governing medical aid in dying was passed in June. The actual number of deaths is probably significantly higher because several provinces could not, or would not, provide complete data. Quebec, which was the first province to adopt a law on doctor-assisted death, provided no data whatsoever. The federal law governing medical aid in dying came into effect June 17, after weeks of passionate, and sometimes very personal, political debate. However, the federal government isn't yet officially tracking the number of deaths. <http://goo.gl/vqBILa>

## U.S.A.

### Hospice care improves patient experience

*REUTERS HEALTH NEWS* | Online – 2 September 2016 – A new study adds to evidence that hospice care during the last six months of life is associated with better overall experiences for patients and a lower likelihood of dying in a hospital.<sup>1</sup> Research team studied more than 163,000 patients enrolled in Medicare, the U.S. government’s insurance for the elderly and disabled, who had died in 2010. All had been hospitalized at least once in the previous two years for a chronic illness associated with high mortality rates. Roughly 47% of patients were in hospice in the last six months of their life. Hospice admissions were tied to a number of variables, the researchers found, including higher patient satisfaction ratings, better pain control, reductions in hospital days, fewer deaths in the hospital, and fewer deaths occurring with an ICU stay during hospitalization. <http://goo.gl/Vm2JYD>

1. ‘Exploring the association of hospice care on patient experience and outcomes of care,’ *BMJ Supportive & Palliative Care*, 16 August 2016. <http://goo.gl/2vaFMR>

## From the hospital to the streets: Madison's homeless need health care, respite, hospice

WISCONSIN | *The Wisconsin State Journal* (Madison) – 28 August 2016 – In Madison, home to one of the nation's acclaimed health care systems, the homeless can needlessly suffer. Some don't get care until illness or dental needs become acute. Mothers with newborns and those recovering from surgery can be discharged to the streets. The terminally ill may have no place to die with dignity. Many need mental health or substance abuse treatment. Others suffer from untreated diabetes, heart disease, infections, foot or dental problems and are unable to get medications. Some are diagnosed too late to be helped or lack insurance. Transportation is a challenge. A lack of cell phones or minutes on

them can undermine scheduling appointments, and getting lab results and instruction. In late 2009, with support from the Meriter Foundation, a street medicine program called Helping Educate & Link the Homeless, was started to help overcome barriers and navigate complexities of the system. <http://goo.gl/YuZTvc>

### Specialist Publications

'Racial and ethnic differences in end-of-life Medicare expenditures' (p.10), in *Journal of the American Geriatrics Society*.

**N.B.** Meriter Foundation, Helping Educate & Link the Homeless: <http://goo.gl/tUWmiF>

Noted in Media Watch 8 August 2016, #474 (p.12):

- *SOCIAL WORK & SOCIETY*, 2016;14(1). 'Serious illness and end-of-life care in the homeless: Examining a service system and a call for action for social work.' In attempting to support the dignity and worth of the patients, social workers should advocate for better discharge practices, and should gain more direct familiarity with the needs of serious and chronically ill homeless individuals. <http://goo.gl/UiG8EB>

**N.B.** Additional articles on end-of-life care for the homeless noted in Media Watch 14 March 2016, #453 (pp.14-15).

## Federal Trade Commission charges academic journal publisher OMICS Group deceived researchers

FEDERAL TRADE COMMISSION | Online – 26 August 2016 – The Commission has charged the publisher of hundreds of purported online academic journals with deceiving academics and researchers about the nature of its publications and hiding publication fees ranging from hundreds to thousands of dollars. The complaint alleges that OMICS Group, Inc., along with two affiliated companies and their president and director, Srinubabu Gedela, claim that their journals follow rigorous peer-review practices and have editorial boards made up of prominent academics. In reality, many articles are published with little to no peer review and numerous individuals represented to be editors have not agreed to be affiliated with the journals. According to the Commission's complaint, OMICS does not tell researchers that they must pay significant publishing fees until after it has accepted an article for publication, and often will not allow

researchers to withdraw their articles from submission, thereby making the research ineligible for publication in another journal. Academic ethics standards generally forbid researchers from submitting the same research to more than one journal. <http://goo.gl/9gQpbt>

The OMICS Group of publications include the *Journal of Palliative Care & Medicine*: <http://goo.gl/ieTbLZ>.

### Specialist Publications

'The dark side of dissemination: Traditional and open access versus predatory journals' (p.14), in *Nursing Education Perspectives*.

**N.B.** Additional articles on predatory journals noted in Media Watch 30 May 2016, #464 (p.11), 11 April 2016, #457 (p.7), 29 February 2016, #451 (p.9), and 8 February 2016, #448 (p.9).

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | *The Denver Post* – 28 August 2016 – **“Dying with dignity” versus “doctor-assisted suicide:” Ballot initiative sets off language battle.** Coloradans in November will decide whether to allow doctors to write life-ending prescriptions for terminally ill people who have less than six months to live and want to die on their own terms. Whether the initiative is called “doctor-assisted suicide,” “dying with dignity” or “medical aid in dying,” though, will depend on who is paying for the campaign ad. The language behind the fight is becoming almost as impassioned as the years-long battle over “pro-choice” and “pro-life” that morphed into “abortion rights supporters” and “abortion rights opponents.” <http://goo.gl/T0Qlo9>

## International

### Elder care in England

#### District nurse cuts “put frail at risk,” report suggests

U.K. (England) | BBC News – 1 September 2016 – The district nursing service in England is at “breaking point” as unmanageable workloads have left patients at risk, a report suggests.<sup>1</sup> The King's Fund review found there had been a big drop in nurse numbers, causing delays and fewer visits. And it described a service where staff had been left “broken and exhausted” by the pressures being placed on them caring for the frail and vulnerable. But National Health Service bosses said attempts were being made to increase staffing. District nursing plays a key role in caring for the elderly, those with disabilities and long-term illnesses, by providing support in their own homes. As well as district nurses, the service includes community matrons

and other nurses. The King's Fund identified official figures showing that district nurse numbers had fallen by 28% in the past five years to just under 6,000, while the wider community nurse workforce had shrunk by 8% to 36,600. <http://goo.gl/IZTnj7>

#### Specialist Publications

**‘Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: Perspectives of older people, carers and other key stakeholders’** (p.7), in *Age & Ageing*.

1. ‘Understanding quality in district nursing services: Learning from patients, carers and staff, The Kings Fund, 1 September 2016. <http://goo.gl/COLR8J>

#### Related

- U.K. | *The Daily Telegraph* – 1 September 2016 – **“Pensioner prisons” could be brought in to cope with ageing inmates.** Pensioner prisons could be introduced to cope with the ageing inmate population, the chief inspector of prisons has said. The increasing numbers of frail prisoners require palliative care and specialist treatment, Peter Clarke said. People over 60 are the fastest-growing age group in custody, with the figure now nearly three times higher than 15 years ago, according to the Prison Reform Trust. <http://goo.gl/6CB8vn>

## End-of-life care in Nigeria

### “Provide palliative for dying patients” – medical expert tells federal government

NIGERIA | Pulse.ng (Lagos) – 31 August 2016 – An Ilorin-based medical practitioner, Dr Grace Oladuni, has urged the federal government to establish palliative healthcare centres across the country for terminally ill patients. Oladuni ... noted that the establishment of the centres will also help to strengthen the health sector. She said that for patients whose deaths are imminent, palliative care (PC) is necessary to alleviate distress symptoms that are common during the last few days or weeks of life. According to her, PC is a resource for everyone living with a serious illness such as cancer, heart failure, dementia, and AIDS among others. She said such centres will also help patients to understand their choices for medical treatment. The medical expert expressed disappointment at the manner

terminally ill patients are being abandoned with little or no care in the hospitals and at homes. Oladuni explained that PC is still novel to the country, owing to the fact that it is not included as an area of acquisition for health professionals across the country. <http://goo.gl/BiI9jR>

#### Specialist Publications

**‘Best practices in developing a national palliative care policy in resource limited settings: Lessons from five African countries’** (p.9), in *ecancermedicalscience*.

**‘End-of-life care in Latin America’** (p.11), in *Journal of Global Oncology*.

Noted in Media Watch 16 November 2015, #436 (p.8):

- AFRICA | *The Mail & Guardian* (Nairobi, Kenya) – 9 November 2015 – **‘Morbid but fascinating: The Quality of Death Index, where South Africa and Uganda lead, and Nigeria trails.’** The Index highlights the advances countries are making in taking care of their citizens at the end of life,<sup>1</sup> as well as the remaining challenges and gaps in policy and infrastructure. Although Africa is still overwhelmingly young, the proportion of older people in the population is rising, and non-communicable diseases such as heart disease, diabetes and cancer are on the rise. The need for palliative care, therefore, is set to rise significantly.

1. Nigeria ranked 77<sup>th</sup> overall of the 80 countries surveyed in the ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, commissioned by the Lien Foundation, October 2015. [Noted in Media Watch 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

## End-of-life care in Australia

### Push to keep palliative care education program to help Tasmanians die at home

AUSTRALIA (Tasmania) | ABC News (Hobart) – 30 August 2016 – More than 700 people have signed a petition to pressure the Federal Government into continuing to fund a Tasmanian education program about dying at home. While Palliative Care Tasmania prepares to wind down the program when its funding runs out at the end of September, the lobby to prevent its demise is gaining momentum. The peak body secured \$2.3 million in mid-2012 under Tasmania’s \$325 million health funding package, but the Government has decided not to renew its funding. The head of the Council of the Ageing in Tasmania, Sue Leitch, said the Better Access to Palliative Care Program was invaluable in demystifying the reality of caring for relatives who wanted to die at home, rather than in acute care wards. <http://goo.gl/YwBZ8h>

Noted in Media Watch 6 October 2014, #378 (p.7):

- AUSTRALIA (Victoria) | Grattan Institute (Melbourne) – September 2014 – **‘Dying well.’** Despite widespread assumptions about the cost of end-of-life care, only about \$5-billion a year is spent on the last year of life for older people in a health budget of \$100-billion. But only about \$100-million is spent on helping people to die at home. A change in focus will not save much, but will help more people to die well. <http://goo.gl/LEPdpP>

## End-of-life care in Scotland

### “Dying patients can struggle to get out-of-hours support”

U.K. (Scotland) | *The Herald* (Glasgow) – 30 August 2016 – Most health boards in Scotland are failing to provide special support for dying patients who are dying during evenings and weekends, an investigation has found.<sup>1</sup> Just one out of 15 health authorities provides a “comprehensive service” out-of-hours for dying patients and families to turn to from home, according to the research... The charity says its their survey found nine health boards, including National Health Service Greater Glasgow & Clyde, do not provide “any meaningful 24/7 support for people who are dying and their family and carers.” Meanwhile, others have dedicated helplines staffed by nurses who are experts in palliative care. The charity unveiled its their findings as new figures were released showing how much time people in Scotland spend at home – rather than in hospital – during the last six months of their lives. The data was expected to show little improvement in the amount of time people are able to spend at home. <http://goo.gl/W2KISb>

1. ‘Dying Doesn’t Work 9 – 5,’ Sue Ryder Scotland, August 2016. <http://goo.gl/lq7wch>

N.B. To read the full briefing, click on

[Read our full briefing >](#)

Noted in Media Watch 21 December 2015, #441 (p.8):

- U.K. (Scotland) | STV News (Glasgow) – 18 December 2015 – ‘**Everyone to have palliative care access, pledges Scottish Government.**’ Palliative care will be made available to every Scot, regardless of diagnosis, in a new government strategy backed by a £3.5 million investment...<sup>1</sup> <http://goo.gl/nqudyp>
  1. ‘Strategic Framework for Action on Palliative & End-of-Life Care,’ Scottish Government, December 2015. <http://goo.gl/CKePiU>

Noted in Media Watch 21 September 2015, #428 (p.6):

- U.K. (Scotland) | *The Courier* (Dundee) – 15 September 2015 – ‘**Report says 10,000 people miss out on palliative care before dying.**’ More than 10,000 Scots who could benefit from palliative care towards the end of their life die without receiving it, a new report has suggested.<sup>1</sup> <http://goo.gl/4JWxaz>
  1. ‘International comparisons in palliative care provision: What can the indicators tell us?’ Health & Sport Committee, September 2015. <http://goo.gl/KhqtqU>

## End-of-life care in England

### New crisis care centre for Cornwall

U.K. (England) | Pirate FM Radio (Redruth) – 29 August 2016 – St Luke’s Hospice is based in Plymouth and ... is expanding to cover the Duchy [of Cornwall] and support hundreds of people with end-of-life care (EOLC). People will be able to access the new 24-hour specialist nursing service... The pilot initiative provides terminally ill patients a 72-hour window of specialist care at home to stabilise symptoms, avoid any unnecessary admission to hospital or facilitate rapid discharge from hospital or hospice back home. The team will work in close partnership with other community health and social care providers in east Cornwall to enhance EOLC services and offer solutions to crisis situations where a patient does not have care arrangements in place. For example, if they need to quickly return home from hospital and their family needs help to look after them. <http://goo.gl/0Ge8Hp>



‘Living and dying in pain: It doesn’t have to happen’  
8 October 2016  
<http://goo.gl/iKZH4k>

## Specialist Publications

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

#### **Developing a model of short-term integrated palliative and supportive care for frail older people in community settings: Perspectives of older people, carers and other key stakeholders**

*AGE & AGEING* | Online – 1 September 2016 – Understanding how best to provide palliative care for frail older people with non-malignant conditions is an international priority. The authors conducted two expert consultations, a consensus survey, and three focus groups. Potential benefits of short-term integrated palliative and supportive care services (SIPS) included holistic assessment, opportunity for end-of-life discussion, symptom management and carer reassurance. Older people and carers advocated early access to SIPS, while other stakeholders proposed delivery based on complex symptom burden. A priority for integrated working was the assignment of a key worker to co-ordinate care, but the assignment criteria remain uncertain. Key stakeholders agree that a model of SIPS for frail older people with non-malignant conditions has potential benefits within community settings, but differ in opinion on the optimal timing and indications for this service. <http://goo.gl/Sv2oQz>

Noted in Media Watch 8 August 2016, #474 (p.7):

- *BRITISH JOURNAL OF COMMUNITY NURSING*, 2016;21(8):385-389. **'Frailty: A term with many meanings and a growing priority for community nurses.'** This article discusses what frailty is, what it may mean for patients, and attempts to expand on why the construct of frailty is a prevalent issue for community nurses. The link between frailty and mortality is discussed and how targeted appropriate advanced care planning may be used to address this demographic challenge. <http://goo.gl/aP7nS9>

**N. B.** Additional articles on end-of-life care (EOLC) for frail older people are noted in this issue of Media Watch. See also selected articles on EOLC for the oldest old noted in the weekly report 29 August 2016, #477 (p.7).

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

#### **Overcoming legal impediments to Physician Orders for Life-Sustaining Treatment**

*AMA JOURNAL OF ETHICS*, 2016;18(9):861-868. The Physician Orders for Life-Sustaining Treatment (POLST), otherwise known as the POLST paradigm, represents the next generation in end-of-life (EOL) planning for certain patients who wish to exercise prospective control over their own medical treatment in their final days. As is true for any physician treatment orders, a POLST is written in consultation with the patient or patient's surrogate. There are a number of practical impediments to widespread adoption and implementation of the POLST paradigm in medical practice. One of these impediments has to do with some physicians' anxiety about potential negative legal repercussions they might suffer for writing or following a patient's POLST... After describing the POLST paradigm and physicians' anxieties about it, this article argues that the feared potential negative legal consequences of writing or following a patient's POLST are not well founded. Instead of succumbing to legal and ethical paralysis, resulting in the failure to integrate the POLST paradigm robustly into practice, physicians should feel comfortable under current and developing law to write and honor POLSTs for appropriate patients. <http://goo.gl/97ynBU>

Noted in Media Watch 11 July 2016, #470 (p.13):

- *HEC FORUM* | Online – 8 July 2016 – **'Failure of the current advance care planning paradigm: Advocating for a communications-based approach.'** Physician Orders for Life Sustaining Treatment (POLST) has been described as a paradigm shift to address the inadequacies of advance directives (ADs). However, POLST has failed to bridge the gap between patients and their autonomous, preferred end of life care decisions. Analysis of ADs and POLST reveals that future policy should focus on a communications-based approach to ACP that emphasizes ongoing interactions between healthcare providers and patients to optimize EOL medical care to the individual patient. <http://goo.gl/QvZLSo>

Cont.

Noted in Media Watch 19 October 2015, #432 (p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – **‘Toward evidence-based end-of-life care.’** More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs despite the absence of compelling evidence that they improve patient outcomes. Even less evidence is available to support such well-intentioned private initiatives as the Institute for Healthcare Improvement Conversation Project, the efforts of the Coalition to Transform Advanced Care, the Gundersen Health System’s Respecting Choices program, the widely used Five Wishes advance directive of the Aging with Dignity organization, and the services provided by for-profit companies such as Vital Decisions and Common Practice. <http://goo.gl/9gFs4X>

### **Palliative care in critical care settings: A systematic review of communication-based competencies essential for patient and family satisfaction**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 31 August 2016 – There is an emerging literature on the physician competencies most meaningful to patients and their families. However, there has been no systematic review on physician competency domains outside direct clinical care most important for patient- and family-centered outcomes in critical care settings at the end of life (EOL). Physician competencies are an essential component of palliative care (PC) provided at the EOL, but the literature on those competencies relevant for patient and family satisfaction is limited. The competencies identified as critical for the delivery of high-quality PC in critical care settings are prognostication, conflict mediation, empathic communication, and family-centered aspects of care, the latter being the competency most frequently acknowledged in the literature identified. <http://goo.gl/Z8zQuV>

### **Clinical checklists, tick boxes, and other *aides memoire* in end-of-life care in out-of-hours general practice**

*BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 1 September 2016 – Although the 2015 National Institute for Health & Care Excellence (NICE) guidelines<sup>1</sup> “supplement the individual clinical judgement that is needed to make decisions about the level of certainty of prognosis and how to manage any uncertainty,” the difficulties and uncertainties described by Dr. Knights still exist in out-of-hours (OOH) palliative care in the community or general practice setting.<sup>2</sup> Guidance from pathways or protocols can provide a helpful framework for the home healthcare team, including the visiting OOH GP, who may well not know the patient. Insufficient care and treatment in the absence of clear protocols may, as Dr. Knights points out, be a more likely outcome than inappropriate treatment in their presence. A typical GP consultation is undertaken to understand and agree with the patient or relatives what condition management and outcomes can be achieved. Not all boxes need ticking. Relevant ones need to be considered, managed, and reviewed, with a “safety net” that takes into account the variability and uncertainties of health, conditions, and people. In his section on the case for “tick box” end-of-life care, Dr. Knights makes his points well regarding such care in hospital, and the valuable practical assistance to all that accepted protocols or checklists can give. Their absence may make it more difficult to implement NICE guidelines consistently. <http://goo.gl/ogffOz>

1. ‘Care of dying adults in the last days of life,’ National Institute for Health & Care Excellence, December 2015. [Noted in Media Watch 21 December 2015, #441 (p.7)] <https://goo.gl/W7cMmj>
2. ‘In defence of the “tick-box approach”: Why end-of-life care (EOLC) is no exception,’ *British Journal of General Practice*, 2016;66(647):290-291. EOLC in England must be tailored to the needs of dying patients rather than a “tick-box approach.” [Noted in Media Watch 30 May 2016, #464 (p.9)] <http://goo.gl/MV5ext>

Noted in Media Watch 8 September 2016, #374 (p.7):

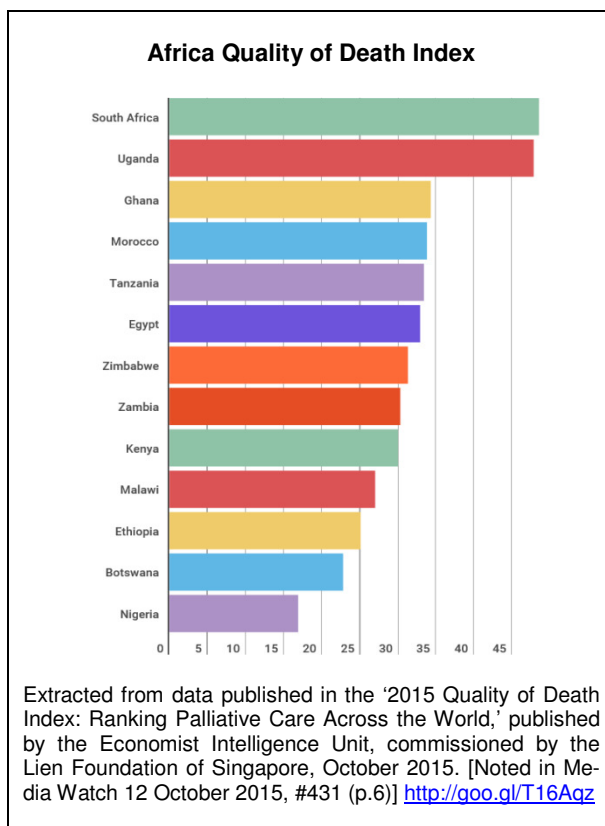
- *BRITISH MEDICAL JOURNAL* | Online – 29 August 2014 – **Talking about death is not outrageous – reducing it to a tick box exercise is.’** Tick-box forms always insist on binary answers. But life is complicated and messy, and being ill, alone, or scared can make us vulnerable. Talking about death is not a bad thing to do, but when health professionals are driven by a policy designed to save money rather than serve patients, we hardly deserve our patients’ trust. <http://goo.gl/SPMDWf>



## Best practices in developing a national palliative care policy in resource limited settings: Lessons from five African countries

eCANCERMEDICALSCIENCE | Online – Accessed 30 August 2016 – There are several lessons learnt from each of the countries where a national palliative care (PC) policy has been developed. Firstly, there should be assessments performed prior to policy development to help countries identify key gaps that need to be covered and addressed by policy implementation. This will include models for PC delivery that need strengthening as well as training and human resource needs. Secondly, PC policy development commits governments to bring back PC both as a discipline and as a service package of health care it must deliver. This is happening in a situation where much of PC has been provided by none-government agencies (NGOs). In addition, this becomes a first step for government to start committing resources, however little to PC delivery. Thirdly, this makes PC advocacy easier across government departments, NGOs, and private sector players within these countries when and if there is a national document that commits government. Fourthly, policies act as a reminder for government to deliver on their regional and global commitments such as the African Common Position on pain medications and controlled substances of 2012 as well as the World Health Assembly PC resolution of 2014. At a regional level, when some countries adopt their PC policies it becomes easier to engage other countries without having to support them to develop theirs. Finally, the presence of national PC policies helps other re-

gional and global entities to create awareness about PC and also lobby for more funding for PC. <http://goo.gl/L7bdd0>



### Related

- 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. Oral morphine is available in hospital PC units. 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>
- eCANCERMEDICALSCIENCE | Online – Accessed 30 August 2016 – '**Integration of legal aspects and human rights approach in palliative care delivery – the Nyeri Hospice model.**' In the absence of a clear legal provision expressly recognising palliative care (PC) in Kenya, providers may face numerous legal and ethical dilemmas that affect the availability, accessibility and delivery of PC services and commodities. Access to legal services remains a big challenge in Kenya, with limited availability of specialised legal services for health-related legal issues. An increased awareness of the benefits of legal services in PC will drive demand for easily accessible and more affordable direct legal services to address legal issues for a more holistic approach to quality PC. <http://goo.gl/InfYmF>

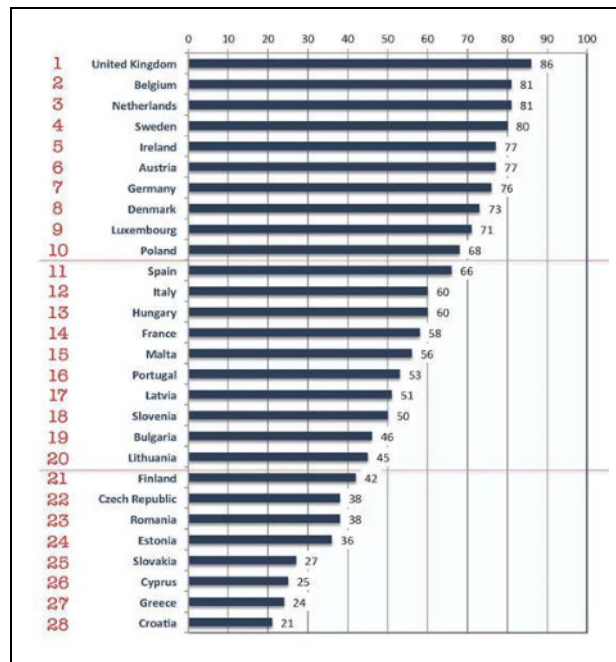
Cont.

- eCANCERMEDICALSCIENCE | Online – Accessed 30 August 2016 – ‘The Island Hospice model of palliative care.’ It is the aim of Island Hospice & Healthcare to bring about a positive change in the lives of the many individuals faced with the challenge of being affected by cancer-related terminal illness. This is carried out through various elements of research, capacity building, direct care, and the constant revision of outcomes of projects implemented by Island. <http://goo.gl/6vHMNn>

### Ranking of palliative care development across Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 31 August 2016 – For the purposes of this study, palliative care (PC) development is understood as a combination of the existence of services in a country (what they have called “resources”) and the capacity to develop further resources in the future (“vitality”). “Resources” comprise three types of indicators of PC services per population (inpatient PC units and inpatient hospices [IPCU], hospital support teams [HST] and home care teams [HCT]). “Vitality” indicators took into account the existence of a national association, a directory of services, physician accreditation, attendances at key European conferences and the volume of publications on PC development. For the ranking construction itself, the leading country (by raw score) was then considered as the reference point against which all other countries were measured. What the authors found out was that the U.K. achieved the highest level of development, followed by Belgium and The Netherlands, and Sweden. With regard to resources only, Luxembourg, the U.K. and Belgium were leading whereas in vitality, Germany and the U.K. got the best results. This ranking was recently pub-

lished in the *Journal of Pain & Symptom Management*.<sup>1</sup> <http://goo.gl/EAckcm>



1. ‘Ranking of palliative care development in the countries of the European Union.’ *Journal of Pain & Symptom Management*, 7 June 2016. [Noted in Media Watch 13 June 2016, #466 (p.11)] <http://goo.gl/B3G4Ya>

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

#### Racial and ethnic differences in end-of-life Medicare expenditures

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 1 September 2016 – The analysis included 5,548 (78.1%) non-Hispanic white, 1,030 (14.5%) non-Hispanic black, and 331 (4.7%) Hispanic adults, and 196 (2.8%) adults of other race or ethnicity. Unadjusted results suggest that average end of life EOL Medicare expenditures were \$13,522 ... more for black decedents and \$16,341 ... more for Hispanics than for whites. Controlling for demographic, socioeconomic, geographic, medical, and EOL-specific factors, the Medicare expenditure difference between groups fell to \$8,047 ... more for black and \$6,855 ... more for Hispanic decedents than expenditures for non-Hispanic whites. The expenditure differences between groups remained statistically significant in all models. Individuals-level factors, including EOL planning factors do not fully explain racial and ethnic differences in Medicare spending in the last 6 months of life. <http://goo.gl/cOFBWW>

Cont.

**Related**

- *JOURNAL OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS*, 2016;29(9):38-43. ‘**The benefits of expanded physician assistant practice in hospice and palliative medicine.**’ Patients with advanced or terminal illness, especially racial and ethnic minorities, would benefit from greater access to hospice and palliative care (HPC). Expanding the PA role in these areas would help fill gaps in both access and patients’ understanding of what HPC can offer. <http://goo.gl/2lB15o>
- *MEDICAL CARE* | Online – 30 August 2016 – ‘**Race/ethnicity and end-of-life care among veterans.**’ Bereaved family members of minority Veterans generally rate the quality of end-of-life care less favorably than those of white Veterans. Family perceptions are critical to the evaluation of equity and quality of end-of-life care. <http://goo.gl/lUkl83>

Noted in Media Watch, 24 August 2015, #424:

- U.S. | National Public Radio – 20 August 2015 – ‘**Can health care be cured of racial bias?**’ Even as the health of Americans has improved, disparities in treatment and outcomes between white patients and black and Latino patients are almost as big as they were 50 years ago. A growing body of research suggests doctors’ unconscious behavior plays a role in these statistics, and the Institute of Medicine of the National Academy of Sciences has called for more studies looking at discrimination and prejudice in health care.<sup>1</sup> <http://goo.gl/JUZvwn>

1. ‘Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,’ Institute of Medicine of the National Academy of Sciences, 2003. <http://goo.gl/C4A9bv>

**End-of-life care in Latin America**

*JOURNAL OF GLOBAL ONCOLOGY* | Online – 24 August 2016 – Cancer has become a global pandemic with disproportionately higher mortality rates in low- and middle- income countries, where a large fraction of patients present in advanced stages and in need of end-of-life care (EOLC). Globally, the number of adults needing EOLC is greater than 19 million, and up to 78% of these patients are living in low- and middle-income countries. In the Americas alone, more than one million people are in need of EOLC, placing an enormous burden on local health systems, which are often unprepared to meet the challenge presented by this complex patient population. In Latin America, cancer care is characterized by the presence of vast inequalities between and within countries, and the provision of EOLC is no exception. Disparities in access to advanced care planning, with a lack of provision of adequate palliative care (PC) and pain medication, are common in the region. These shortcomings are related in large part to inadequate or inappropriate legislation, lack of comprehensive national PC plans, insufficient infrastructure, lack of opportunities for clinical training, unreliable reporting of data, and cultural barriers. This report reviews the current status of

EOLC in Latin America, focusing on identifying existing deficiencies and providing a framework for improvement. <http://goo.gl/W7143A>

Country	National Law	National Cancer Program Including Palliative Care	National Primary Care Program Including Palliative Care
Argentina	No	Yes	No
Bolivia	No	Yes	No
Brazil	No	Yes	Yes
Chile	No	Yes	Yes
Colombia	Yes	Yes	No
Costa Rica	No	Yes	Yes
Cuba	No	Yes	Yes
Dominican Republic	No	No	No
Ecuador	No	Yes	No
El Salvador	No	No	No
Guatemala	No	Yes	No
Honduras	No	No	No
Mexico	Yes	Yes	No
Nicaragua	No	Yes	No
Panama	Yes	Yes	Yes
Paraguay	No	Yes	No
Peru	No	Yes	Yes
Uruguay	Yes	Yes	Yes
Venezuela	No	Yes	Yes

Cont.

Noted in Media Watch 19 October 2015, #432 (p.7-8):

- CHILE | *PanAm Post* (Miami, Florida) – 9 October 2015 – ‘**Chile ranks Latin America’s best for treatment of the dying.**’ Chile is the best country in which to die in Latin America, according to a study conducted by the Economist Intelligence Unit (EIU).<sup>1</sup> Coming in near the bottom of the list, the EIU’s ‘2015 Quality of Death Index’ ranks Guatemala and the Dominican Republic at 74th and 75th, respectively of the 80 countries surveyed. Puerto Rico [46th], Peru [49th], and Colombia [68th] also received low scores. According to the report, local governments in these countries have introduced strategies for the development of palliative care (PC) – but, there are no clear mechanisms for its implementation. At the top of the list of regional countries, Chile [at 27th] is followed by Costa Rica [29th] and Panama [31st] as the best places to die in Latin America. The EIU highlights the Chilean government’s efforts to “incorporate PC into health care services and to develop policies for that purpose.” The report also notes that there are sufficient specialized PC professionals in Chile, as well as access to medication, yet the latter is “restricted by bureaucratic red tape.” <http://goo.gl/MQK0zD>

1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, commissioned by the Lien Foundation of Singapore, October 2015. [Noted in Media Watch 12 October 2015, #431 (p.6)] <http://goo.gl/JsSbW3>

Noted in Media Watch 9 February 2015, #396 (p.16):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 February 2015 – ‘**Palliative care in Latin America from the professional perspective: A SWOT analysis.**’ A Strengths, Weaknesses, Opportunities, and Threats analysis may contribute to the identification of barriers and successful strategies. A total of 577 expert statements were provided. Among the strengths were integration into health systems and increasing number of professionals with palliative care (PC) training. Among weaknesses were lack of national PC programs, limited connection between policymakers and professionals, and barriers in the availability of opioids. <http://goo.gl/o8ya8K>

**N.B.** See also ‘Atlas de Cuidados Paliativos de Latinoamérica,’ Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch 7 January 2013, #287, (p.8)] Spanish language edition: <http://goo.gl/5SI47I>; Portuguese: <http://goo.gl/0UrRUy>; English: <http://goo.gl/ebRtXn>.

### **Burdens versus benefits: When family has to decide how much is too much**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(5):382-387. Advanced directives allow patients to designate an agent to make decisions for them if they become incapacitated and unable to make their own decisions. Unfortunately, designating an agent does not ensure that that person understands the patient’s preferences for treatment or has the ability to carry out the patient’s wishes. This can leave end-of-life decision making up to individuals who may not be able to understand medically what is happening and may be too emotionally invested to make difficult decisions. Families may request non-beneficial treatments in these situations that can raise ethical issues such as autonomy and nonmaleficence. Conflict within the family and between the family and health care team regarding the burdens and benefits of further treatment can lead to moral distress. <http://goo.gl/hMRbcR>

#### **Related**

- *JOURNAL OF NURSING ADMINISTRATION* | Online – 26 August 2016 – ‘**Honoring patient requests: A volunteer initiative to support the presence of advance directives.**’ Hospitals seeking to support advance care planning and the execution of advance directives face challenges in matching patient readiness with the availability of knowledgeable personnel and resources. A volunteer-based advance directive team represents an innovative approach to providing personalized, timely, and accurate information about advance directives and assisting patients with their completion. <http://goo.gl/ohzq0t>

### **Closing the Gap Between Knowledge & Technology**

Fostering education and interaction, and the exchange of ideas, information and materials.

<http://goo.gl/OTpc8I>



## **The impact of palliative care consultation in the ICU on length of stay: A systematic review and cost evaluation**

*JOURNAL OF INTENSIVE CARE MEDICINE* | Online – 31 August 2016 – The intensive care unit (ICU) consumes 20% of hospital expenditures and 1% of gross domestic product. Many strategies have been attempted to reduce ICU costs. The authors reviewed 814 abstracts, but only 8 studies met inclusion criteria and were included. The patients with a palliative care (PC) consultation in the ICU, when compared to those who did not, showed a trend toward reduced length of stay (LOS). PC consultations also lead to a reduction in costs in 5 of the 8 eligible trials. On average, ICU costs were USD7533 and USD6406 ... and hospital direct variable costs were USD9518 and USD8971... This review demonstrates a trend that PC consultations reduce LOS and costs without impacting mortality. However, due to the small sample sizes and varying degrees of quality of evidence, many questions remain. <http://goo.gl/uV8kOa>

Noted in Media Watch 25 January 2016, #446 (p.7):

- *ANNALS OF THE AMERICAN THORACIC SOCIETY* | Online – 19 January 2016 – ‘**Palliative care for patients dying in the ICU with chronic lung disease compared to metastatic cancer.**’ The authors explored differences in receipt of elements of palliative care (PC) for patients with interstitial lung disease (ILD) and chronic obstructive pulmonary disease (COPD) who die in ICUs compared to patients with cancer. Among patients who die in the ICU, patients with ILD and COPD receive fewer elements of PC and have longer lengths of stay compared to patients with cancer. These findings identify areas for improvement in caring for patients with chronic lung diseases. <http://goo.gl/1GvhiR>

Noted in Media Watch 22 September 2014, #376 (p.11):

- *CURRENT OPINION IN CRITICAL CARE* | Online – 12 September 2014 – ‘**Economic implications of end-of-life care in the ICU.**’ The authors identified three studies assessing the impact of palliative care (PC) consultation on ICU admissions for patients with life-limiting illness; all demonstrate reduced ICU admissions for patients receiving PC consultation. Among 16 studies evaluating ICU length of stay (LOS) as an outcome, five report no change and 11 report decrease in LOS for patients receiving advance care planning or PC. <http://goo.gl/ElrqDY>

## **Futility disputes: A review of the literature and proposed model for dispute navigation through trust building**

*JOURNAL OF INTENSIVE CARE MEDICINE* | Online – 27 August 2016 – Futility disputes in the intensive care unit setting have received significant attention in the literature over the past several years. Although the idea of improving communication in an attempt to resolve these challenging situations has been regularly discussed, the concept and role of trust building as the means by which communication improves and disputes are best navigated is largely absent. The authors review the current literature on futility disputes and argue the important role of broken trust in these encounters, highlighting current evidence establishing the necessity and utility of trust in both medical decision-making and effective communication. They propose a futility dispute navigation model built upon improved communication through trust building. <http://goo.gl/FychEG>

### **Selected articles on medical futility in the context of end-of-life care**

- *AMERICAN JOURNAL OF BIOETHICS*, 2016;16(7):58-60. ‘**Palliative care ethics: A case commentary on discontinuing interventions at the end of life.**’ Some hospitals never permit health care providers to override patient/surrogate requests for such interventions. Many other hospitals have futility policies that only permit overriding patient/surrogate requests for physiologically futile interventions. Some hospitals permit health care teams to withhold interventions that a health care team (or review body) deems to be futile... [Noted in Media Watch 27 June 2016, #468 (p.7)] <http://goo.gl/4MzH0Y>

Cont.

- *CHEST* | Online – 11 June 2016 – ‘**Reason-giving and medical futility: Contrasting legal and social discourse in the U.S. with the U.K. and Ontario, Canada.**’ The authors describe recent cases from different countries (the U.S., U.K., and Canada) to qualitatively contrast the legal responses to intractable, policy-level disputes regarding end-of-life care in each of these countries. The authors argue precedential, publicly available, written rulings for these decisions most effectively help to move the social debate forward in a way that is beneficial to clinicians, patients, and citizens. [Noted in Media Watch 27 June 2016, #468 (p.7)] <http://goo.gl/D2xCso>
- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online – 17 December 2015 – ‘**Medically inappropriate or futile treatment: Deliberation and justification.**’ This paper reframes the futility debate, moving away from the question “Who decides when to end what is considered to be a medically inappropriate or futile treatment?” and toward the question “How can society make policy that will best account for the multitude of values and conflicts involved in such decision-making?” [Noted in Media Watch 21 December 2015, #441 (p.14)] <http://goo.gl/0Ucl2W>

### **Physician-reported symptoms and interventions in people with intellectual disabilities approaching end of life**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 September 2016 – Eighty-one physicians for people with IDs (ID-physicians) completed a retrospective survey about their last patient with IDs with a non-sudden death. On average, patients suffered from three of the eight Edmonton Symptom Assessment System symptoms. Fatigue, drowsiness, and decreasing intake were most reported. ID-physicians reported a median number of four interventions. Interventions were mostly aimed at somatic problems, such as pain and shortness of breath. Burdensome interventions, such as surgery or artificial respiration, were least or not reported. Palliative sedation was provided in a third of cases. Although ID-physicians reported a variety of their patients’ symptoms and of provided interventions at the end of life, using adequate symptom assessment tools suitable for people with IDs and continuous multidisciplinary collaboration in palliative care are essential to capture symptoms as fully as possible. <http://goo.gl/g2dnDV>

Noted in Media Watch 15 August 2016, #475 (p.12):

- *RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2016;59(12):55-64. ‘**Physicians’ identification of the need for palliative care in people with intellectual disabilities.**’ Identification of people with intellectual disabilities (ID) in need for palliative care (PC) mostly results from a process in which multiple signals from different information sources converge and lead to a growing awareness. As a result, ID-physicians do not expect people to return to their prior level of health or functioning, but rather expect an irreversible decline leading to death. <http://goo.gl/0AuHy9>

**N.B.** Additional articles on palliative care for people living with intellectual disabilities are noted in Media Watch 1 August 2016, #473 (p.14), and 8 February 2016, #448 (p.12).

### **The dark side of dissemination: Traditional and open access versus predatory journals**

*NURSING EDUCATION PERSPECTIVES*, 2016;37(5):275-277. Characteristics of scholarly open access (OA) journals are compatible with many characteristics of traditional journals, including the four key criteria of archiving/preservation, reputable board members, indexing, and peer review. Characteristics of predatory OA journals are not compatible with the identified traditional journal characteristics. Thus, authors need to complete due diligence in reviewing both publisher and journal with the help of the aforementioned resources and then decide where and whether to submit a manuscript for publication. Do not prematurely limit publication possibilities because of professional blindness toward “author-pays” requirements, while evaluating opportunities for publication in scholarly OA journals. In addition, promotion and tenure committees need to recognize the value of OA publications. Finally, check Beall’s list of predatory publishers (<http://goo.gl/EQOVzw>) to identify predatory publishers and the Directory of Open Access Journals after March 2014 (<http://goo.gl/KuHA69>) to identify safe journals before submitting a manuscript. Be sure to caution students about the identification/use of predatory publications. <http://goo.gl/dAKfSs>

**N.B.** Additional articles on predatory journals noted in Media Watch 30 May 2016, #464 (p.11), 11 April 2016, #457 (p.7), 29 February 2016, #451 (p.9), and 8 February 2016, #448 (p.9).

## Culture and palliative care

*NURSING OLDER PEOPLE*, 2016;21(3):14. In palliative care (PC) the notion of a good death is based on patients being fully aware of their diagnosis and prognosis. This does not necessarily reflect different social, cultural and spiritual beliefs. In the U.K. people from minority ethnic communities access fewer PC services. Staff often had difficulty managing basic needs such as communication with non-English speakers, the halal diet (that which is allowed in Islam), and the need for specific hygiene practices such as wudu (ritual washing preceding daily prayers) and istinja (washing with free flowing water after urination or bowel movement). <http://goo.gl/srjN2b>

**N.B.** Additional articles on end-of-life care from the Islamic perspective are noted in Media Watch 1 February 2016, #447 (pp.13-14).

## New guidelines on patient resuscitation for Scotland

*NURSING TIMES* | Online – 31 August 2016 – The national policy on do not attempt cardiopulmonary resuscitation (DNACPR) for adults in Scotland has been updated, with an emphasis on open discussion with patients and relatives. It follows a review of both adult and children's policies in order to reflect changes in national good practice guidance. The update emphasises the importance of engaging with patients and their families about CPR decision-making in the "context of the goals of care, realistic treatment options and choices." Where CPR will not help and may cause harm and distress for the patient and their family, the policy states that there should be a "presumption in favour of informing patients of a DNACPR decision." "This information should always be shared sensitively in the context of exploring their goals of care and wishes around realistic emergency treatment options," stats the guidance. Other key points in the updated guidance concern when CPR will not be successful and a DNACPR decision has been made and documented. The "only justification for not sharing this information" with a patient is where they lack capacity to engage with the conversation, in which case the information must be shared with the welfare attorney/guardian or relevant others as soon as possible, the patient refuses to engage or it is judged that the conversation would "cause the patient physical or psychological harm." The updated document also said that, where a clinical team is as certain as it can be that CPR will not be successful and that the patient is irreversibly deteriorating, the DNACPR decision "will remain appropriate until the patient's death and does not need reviewed." <http://goo.gl/QcECbk>

1. 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR),' Government of Scotland, August 2016. <http://goo.gl/DO1q0m>

**N.B.** Selected articles on resuscitation policies and practices in various countries noted in Media Watch 29 August 2016, #477 (p.13).

## Hospice palliative care volunteers' experiences with unusual end-of-life phenomena

*OMEGA* | Online – 1 September 2016 – Forty-five Canadian hospice palliative care volunteers responded to a survey examining whether they had witnessed or been told about any unusual end-of-life phenomena (EOLP) in their work with dying patients and their families in the past year. The most commonly witnessed EOLP were patients talking to or reaching out their hands toward deceased relatives or friends, occurrences of terminal lucidity, and patients seemingly getting ready for a trip or journey. At least a third of the volunteers indicated that a patient or a patient's family member had told them about visions or dreams of deceased relatives or friends, seeing beautiful places or colors or hearing wonderful music, terminal lucidity, and deathbed coincidences. The majority of volunteers were accepting of spiritual explanations for EOLP and rejecting of scientific or medical ones. Ninety-six percent of the volunteers felt that information about EOLP should be included as part of their volunteer training. <http://goo.gl/UV74Xg>

**N.B.** Additional articles on deathbed and end-of-life phenomena noted in Media Watch 15 August 2016, #475 (p.10).

## Collaboration: Securing a future for palliative care research

*PALLIATIVE MEDICINE*, 2016;30(8):709-710. There is potentially something to be gained for everyone by increasing palliative care (PC) research collaboration. In a recent editorial<sup>1</sup> ... Higginson reviews current challenges for PC research, both in terms of the U.K.'s research agenda responsiveness to national policy and through key messages to funding agencies to ensure that research effectively translates into better patient and family care at the end of life. A specific call for greater collaboration (both nationally and internationally) is made. She is not the first. An editorial<sup>2</sup> by Stein Kaasa in 2008 at the advent of the European Palliative Care Research Collaborative called for "an international arena for PC research." Has this been achieved? Particularly at this time of confusion for the U.K. in light of the recent referendum decision to leave the European Union and the vacuum that leaves in terms of a clear understanding of its implications for future research partnership, it is critical to understand how robust international collaboration can be achieved and what practical steps are needed to foster success. <http://goo.gl/ECdPkO>

1. 'Research challenges in palliative and end of life care,' *BMJ Supportive & Palliative Care*, 2016;6(1):2-4. [Noted in Media Watch 22 February 2016, #450 (p.10)] <http://goo.gl/WNJelB>
2. 'Palliative care research – time to intensify international collaboration,' *Palliative Medicine*, 2008;22(4): 301-302. <http://goo.gl/bGt57B>

**N.B.** To access full text click on [Full Text \(PDF\)](#)  Free

### Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 August 2016 – '**Trust building recruitment strategies for researchers conducting studies in African American churches: Lessons learned.**' Mistrust of medical research is an extremely important barrier hindering recruitment in African American communities. A church-based end-of-life dementia education project is currently being conducted at four large urban African American churches. Church leaders voiced mistrust concerns of previous researchers who conducted investigations in their faith-based institutions. The authors explored strategies to ameliorate the mistrust concerns. <http://goo.gl/i8ccMR>

## Spiritual beliefs, practices, and needs at the end of life: Results from a New Zealand national hospice study

*PALLIATIVE & SUPPORTIVE CARE* | Online – 30 August 2016 – International studies have shown that patients want their spiritual needs attended to at the end of life. The authors developed a project to investigate people's understanding of spirituality and spiritual care practices in New Zealand (N.Z.) hospices. Their findings suggest that spirituality is broadly understood and considered important for all three of the populations studied. The patient and family populations had high spiritual needs that included a search for – 1) Meaning; 2) Peace of mind: and, 3) A degree of certainty in an uncertain world. The healthcare professionals in the hospices surveyed seldom explicitly met the needs of patients and families. Staff had spiritual needs, but organizational support was sometimes lacking in attending to these needs. As a result of this study, which was the first nationwide study in N.Z. to examine spirituality in hospice care, Hospice New Zealand has developed a spirituality professional development program. Given that spirituality was found to be important to the majority of our participants, it is hoped that the adoption of such an approach will impact on spiritual care for patients and families in N.Z. hospices. <http://goo.gl/xGWEv5>

**N.B.** Additional articles on spirituality in the context of end-of-life care noted in Media Watch 22 August 2016, #476 (p.8), 27 Jun 2016, #468 (pp.9-10), 4 April 2016, #456 (p.7), and 8 June 2015, #413 (pp.10-11).

### [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.20.



## Integrating pediatric palliative care into the school and community

*PEDIATRIC CLINICS OF NORTH AMERICA*, 2016;63(5):899-911. Children and adolescents with complex chronic conditions often receive pediatric palliative care (PPC) from health care professionals. However, children's needs exist both in a health care context and in the community where children interact with peers, including school, places of worship, sports, activities, and organizations. Partnerships between PPC professionals in health care settings and teachers, coaches, spiritual leaders, activity directors, and others, may lead to greater health and well-being. Children near the end of life or those with out-of-hospital do-not-resuscitate orders may also find palliation in their community. Coopera-

tion between all caregivers benefit the child and family. <http://goo.gl/wpZ126>

### Extract from *Pediatric Clinics of North America* article

Education and civil rights legislation provide a foundation for comprehensive pediatric palliative care services in schools and community settings. When a child has an out-of-hospital do-not-resuscitate order, health care providers should partner with schools to provide support to the child and family, as well as to school professionals, to ensure a positive outcome for all parties.

Noted in Media Watch 25 January 2016, #446 (p.3):

- U.S. (Alabama) | *The Decatur Daily* – 21 January 2016 – ‘**Mother, school district reach agreement on terminally ill student.**’ Limestone County Schools has reversed its previous position and reached an agreement with the mother of a terminally ill student that allows the mother and the student's hospice nurse to be on campus with him. The school district has never denied Alex, a freshman, access to school, but the district refused to comply with an advanced directive prepared by the family's attorney, which essentially requested Alex not be provided lifesaving medical care if he had medical problems at school. <http://goo.gl/KxOlxd>

## Preparing the pediatric dentist for palliative and end-of-life care

*PEDIATRIC DENTISTRY*, 2016;38(4):295-299. Pediatric dentists may feel ill prepared to assume the roles and responsibilities of a pediatric palliative care (PC) provider due to limited education and training during dental school and residency; however, they should be sensitive to the PC needs of children and families. The purpose of this clinical article was to highlight PC scenarios in pediatric dentistry and provide actionable resources to empower pediatric dentists to gather health care information, make informed ethical decisions, promote patient- and family-centered care, and prepare dentists and their dental teams for episodes of death and bereavement when providing a dental home to patients with life-threatening and complex chronic conditions. <http://goo.gl/knkvPQ>

## Supporting the grieving child and family

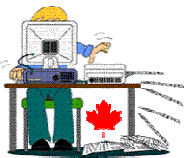
*PEDIATRICS* | Online – 29 August 2016 – This clinical report offers practical suggestions on how to talk with grieving children to help them better understand what has happened and its implications and to address any misinformation, misinterpretations, or misconceptions. An understanding of guilt, shame, and other common reactions, as well as an appreciation of the role of secondary losses and the unique challenges facing children in communities characterized by chronic trauma and cumulative loss, will help the pediatrician to address factors that may impair grieving and children's adjustment and to identify complicated mourning and situations when professional counseling is indicated. Advice on how to support children's participation in funerals and other memorial services and to anticipate and address grief triggers and anniversary reactions is provided so that pediatricians are in a better position to advise caregivers and to offer consultation to schools, early education and child care facilities, and other child congregate care sites. Pediatricians often enter their profession out of a profound desire to minimize the suffering of children and may find it personally challenging when they find themselves in situations in which they are asked to bear witness to the distress of children who are acutely grieving. <http://goo.gl/7NIMJE>

Cont.

## Related

- **AUSTRALIAN CRITICAL CARE** | Online – 25 August 2016 – ‘**The provision of family-centred intensive care bereavement support in Australia and New Zealand: Results of a cross sectional explorative descriptive survey.**’ This is the first Australia and New Zealand-wide survey on ICU bereavement support services. Whilst key components of family bereavement support remain consistent over the past decade, there were fewer bereavement follow-up services in responding Australian ICUs in 2015. As a quality improvement initiative, support for this area of family care remains important with rigorous evaluation essential. <http://goo.gl/8eld66>

Cont. next page



### [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.<sup>1</sup> 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>

1. Ashpole BR. 'Communications with the Public, Politicians, and the News Media,' *Oxford Textbook of Palliative Medicine*, 5<sup>th</sup> Edition (pp.357-359), Oxford University Press, 2015. <https://goo.gl/Vi07RS>.

### [Media Watch: Editorial Practice](#)

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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.

- *THE FAMILY JOURNAL* | Online – 26 August 2016 – ‘**Anticipatory grief: A family systems approach.**’ Anticipatory grief not only affects the life of the person diagnosed with a terminal illness but the family and systems that they belong to. As a family transitions from anticipatory grief through bereavement, changes and adjustments will affect the relationships within the family system. The advantages of supporting the entire family through use of a family systems theoretical framework, as opposed to treating members of the family individually are explored. <http://goo.gl/YyeIFc>
- *INTERNATIONAL JOURNAL OF PALLIATIVE NURSING* | Online – 27 August 2016 – ‘**Exploring the spiritual needs of families with seriously ill children.**’ This research examined the spiritual needs of families based on nurses’ experiences with families of seriously ill children. Nurses’ experiences revealed that families’ anger with God, blame/regret, forgiveness, and ritual and cultural traditions are salient spiritual needs requiring effective nurse communication skills to support families of ill children. <http://goo.gl/DuaK3Q>

### Prognostic disclosures to children: A historical perspective

*PEDIATRICS* | Online – 25 August 2016 – The authors review the historical literature on prognostic disclosure (PD) to children in the U.S. using cancer as an illness model. Before 1948, there was virtually no literature focused on PD to children. As articles began to be published in the 1950s and 1960s, many clinicians and researchers initially recommended a “protective” approach to disclosure, where children were shielded from the harms of bad news. The authors identified 4 main arguments in the literature at this time supporting this “protective” approach. By the late 1960s, however, a growing number of clinicians and researchers were recommending a more “open” approach, where children were included in discussions of diagnosis, which at the time was often synonymous with a terminal prognosis. Four different arguments in the literature were used at this time supporting this “open” approach. Then, by the late 1980s, the recommended approach to PD in pediatrics shifted largely from “never tell” to “always tell.” In recent years, however, there has been a growing appreciation for the complexity of PD in pediatrics. Current understanding of pediatric disclosure does not lead to simple “black-and-white” recommendations for disclosure practices. As with most difficult questions, we are left to balance competing factors on a case-by-case basis. The authors highlight 4 categories of current considerations related to PD in pediatrics, and they offer several approaches to prognostic disclosure for clinicians who care for these young patients and their families. <http://goo.gl/9NgU3x>

Noted in Media Watch 2 May 2016, #460 (p.4):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 April 2016 – “**Don’t try to cover the sky with your hands”: Parents’ experiences with prognosis communication about their children with advanced cancer.**’ Although most parents [i.e., study participants] noted that frank disclosure fostered hope by relieving uncertainty and allowing them to make the best possible decisions for their children. Excessive optimism or a lack of information, in contrast, was sometimes experienced as a threat to hope and the parent-clinician relationship. <http://goo.gl/d5fyWs>

### Worth Repeating

#### Next of kin’s experiences of shame in end-of-life care

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 9 December 2013 – The aim of this study was to gain a greater understanding of the experiences of shame of next of kin in end-of-life care (EOLC). Seventeen next of kin who had lost a family member were interviewed. The results showed that next of kin’s experiences of shame are linked to their perception of the remaining time and are guided by views on morality and what is right and wrong. Shame can occur when the next of kin are involved and actually cause harm to the family member as well as in situations that are beyond their control. Shame can also involve actions that have nothing to do with what they have actually done, but is instead a shame that is placed on them by others, for example, health professionals or relatives. Shame is interpreted as experiences of ignominy, humiliation, and disgrace. Second-order shame is also found. It is important that health professionals are aware of these experiences of unhealthy shame when they meet and support next of kin in EOLC. [Noted in Media Watch 23 December 2013, #337 (p.13)] <http://goo.gl/etV0uJ>

## [Media Watch: Online](#)

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/vjGQws>

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): <http://goo.gl/XrhYCH>

### **Canada**

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

### **Europe**

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

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

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

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