

## 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 ‘Understanding meaning in life interventions in patients with advanced disease: A systematic review and realist synthesis’ (p.16), in *Palliative Medicine*.**

## Canada

### **Invest in palliative care to reduce health costs, say physicians**

CBC NEWS | Online – 15 February 2017 – Investing in palliative care (PC) and hospice programs could improve patient care and reduce health-care costs, says a new report from the Canadian Society of Palliative Care Physicians.<sup>1</sup> According to the Society, investing in hospital-based PC, compared to acute care, could save the health care system up to \$8,000 per patient. Providing PC would enable the more efficient and appropriate use of Canadian health care resources by reducing the costs of caring for people with life-threatening illnesses and freeing up much-needed hospital beds, said society president, Dr. David Henderson in a statement. The report said that shifting 10% of patients at the end of their lives from acute hospital

care to home care would save \$9 million a year. It further estimates that moving patients from acute care to a hospice could reduce patient costs by \$600 per day. According to the society, PC reduces patient anxiety and depression, improves their quality of life and, in some cases, extends life. <https://goo.gl/VVBnfS>

### **Specialist Publications**

**‘Palliative care discussions in multiple system atrophy: A retrospective review’ (p.9), in *Canadian Journal of Neurological Sciences*.**

1. ‘Palliative Care: A vital service with clear economic, health and social benefits,’ Canadian Society of Palliative Care Physicians, February 2017. <https://goo.gl/L03JLu>

Noted in Media Watch 7 November 2016, #486 (p.2):

- CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS | Online – 2 November 2016 – **‘How to improve palliative care in Canada: A call to action for federal, provincial, territorial, regional and local decision makers.’** The Society is calling on politicians at all levels of government to act immediately to improve access to palliative care in Canada. <https://goo.gl/DiBjDx>

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

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | *Ottawa Metro* – 13 February 2017 – ‘**Doctors struggling to cope with assisted death.**’ Since new legislation came into place last year, 28 people in Ottawa have ended their lives with the help of a physician. Advocates say the new legislation, which came into force last June, is taking a toll on some doctors, who are finding it difficult to help patients who want to die. <https://goo.gl/7JPDDt>

## U.S.A.

### Senate weighs bill altering parental rights of medically fragile children

KANSAS | *The Topeka Capital-Journal* – 16 February 2017 – Sheryl Crosier, of St. Louis, urged a Kansas Senate committee ... to endorse legislation requiring parental permission before do-not-resuscitate orders are attached by a physician to the medical file of a minor child. Senate Bill 85 was opposed by the Kansas Hospital Association and other medical providers. Support for the measure – a similar bill passed the Senate last session – came from Lt. Governor Jeff Colyer, the Disability Rights Center of Kansas, Kansans for Life, and the Kansas Catholic Conference. Deborah Stern, senior vice president of clinical services and general counsel with the Kansas Hospital Association, said the Senate bill applicable to care of patients under the age of 18 was drafted despite lack of evidence that issues raised by Crosier had arisen in any Kansas hospital or medical care facility. <https://goo.gl/tzKxYC>

Noted in Media Watch 28 March 2016, #455 (p.3):

- KANSAS | *The Topeka Capital-Journal* – 21 March 2016 – ‘**Senate advances bill on child “do not resuscitate” orders.**’ Health care professionals would be barred from filing “do not resuscitate” orders on patients under 18 years old without parent permission under legislation endorsed by the Kansas Senate. The bill, known as “Simon’s Law,” would prohibit health care professionals from withholding life-sustaining care from patients under 18 without a parent’s consent. <http://goo.gl/CY180b>

### Docs bill Medicare for end-of-life advice as “death panel” fears re-emerge

KAISER HEALTH NEWS | Online – 15 February 2017 – End-of-life (EoL) counseling sessions, once decried by some conservative Republicans as “death panels,” gained steam among Medicare patients in 2016, the first year doctors could charge the federal program for the service. Nearly 14,000 providers billed almost \$35 million – including nearly \$16 million paid by Medicare – for advance care planning (ACP) conversations for about 223,000 patients from January through June... Controversy is threatening to re-emerge in Congress over the funding, which pays doctors to counsel some 57 million Medicare patients on EoL treatment preferences. Representative Steve King, Republican-Iowa, introduced a bill last month, the Protecting Life Until Natural Death Act, which would revoke Medicare reimbursement for the sessions, which he called a “yet another life-devaluing policy.” While the fate of King’s bill is highly uncertain – the recently proposed measure hasn’t seen congressional

action – it underscores deep feelings among conservatives who have long opposed such counseling and may seek to remove it from Medicare should Republicans attempt to make other changes to the entitlement program. Proponents of ACP, however, cheered evidence of program’s early use as a sign of growing interest in late stage life planning. <https://goo.gl/SmBEY4>

#### Specialist Publications

‘**Provider perspectives on advance care planning documentation in the electronic health record: The experience of primary care providers and specialists using advance health-care directives and Physician Orders for Life-Sustaining Treatment**’ (p.7), in *American Journal of Hospice & Palliative Medicine*.

Cont.

## Related

- PENNSYLVANIA | *The Inquirer* (Philadelphia) – 16 February 2017 – ‘**Doctors are confused by living wills, study finds.**’ Interpreting a living will is, by definition, a life-and-death activity. So, it’s not comforting that, when hundreds of doctors were asked to decide what nine different living wills and related documents meant, they rarely agreed. In a new study,<sup>1</sup> the doctors reached consensus – defined as 95% agreement – on only two of the scenarios. If they read the papers and also saw a one-minute video of a patient describing his or her wishes, they agreed on how to treat a third case and reached 94% agreement on a fourth. <https://goo.gl/TqJGA1>
  1. ‘Nationwide multicenter evaluation to determine whether patient video testimonials can safely help ensure appropriate critical versus end-of-life care,’ *Journal of Patient Safety*, published online 14 February 2017. <https://goo.gl/8oKujE>
- *FORBES* | Online – 14 February 2017 – ‘**Advance care planning for procrastinators.**’ Most adults have at least heard of the phrase “advance care planning” (ACP) and know that it has something to do with living wills or medical powers of attorney – documents we generally refer to as advance directives. But most adults have not thought about the fact that everyone has a default advance care plan, regardless of age or health condition. Medical decisions will be made for you when you can no longer make those decisions for yourself. By procrastinating important ACP, however, you are ceding control over your fate to others whose behavior will likely not be primarily driven by devotion to your personal values. <https://goo.gl/Qa6syZ>

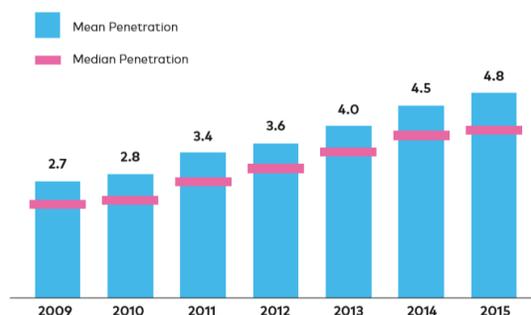
## Palliative care continues to grow with greater diversity in patient diagnoses – wider access still needed

CENTER TO ADVANCE PALLIATIVE CARE & NATIONAL PALLIATIVE CARE RESEARCH CENTER | Online – 13 February 2017 – As the number of Americans living with serious and chronic illness has increased so has the penetration of palliative care (PC) in U.S. hospitals, with programs reaching a larger proportion of hospitalized patients in need. Despite the growth of PC in the U.S. many programs are still not adequately staffed. These and other findings are from ‘How We Work: Trends and Insights in Hospital Palliative Care.’ Key findings: 1) Length of hospital stay: Programs reported an average hospital stay of 10.4 days for PC patients (twice the national average), reflecting the intensity and complexity of the needs of patients with serious illness; 2) Staffing insights: The number of staff dedicated to PC services has steadily increased, especially among the largest hospitals; 3) Service penetration: The percentage of hospitalized patients receiving PC supports has increased from an average of 2.7% of hospital admissions in 2009 to 4.8% in 2015, suggesting greater integration of PC expertise into the routine care of people in the hospital; 4) Top referring specialties: Nearly half (48%) of all PC referrals in 2015 came from hospitalists; 5) Top 4 primary diagnoses: On average, one in four PC patients had a

primary diagnosis of cancer (26%), followed by heart disease (13%), lung disease (12%) and stroke or traumatic brain injury (8%). These diseases are the 4 leading causes of death in the U.S. <https://goo.gl/AB3F64>

### Palliative Care Service Penetration

Palliative care service penetration is the percentage of annual hospital admissions seen by the palliative care team. Over the past 7 years, palliative care penetration has increased by 78%. In 2015, on average, 4.8% of all hospital admissions received palliative care.



### Specialist Publications

‘How can we increase the use of palliative care in Medicare?’ (p.11), in *Health Affairs*.

Cont.

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

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 September 2015 – ‘**The growth of palliative care in U.S. hospitals: A status report.**’ This study demonstrates continued steady growth in the number of hospital palliative care (PC) programs in the U.S., with almost universal access to services in large hospitals and academic medical centers.<sup>1</sup> Nevertheless access to PC remains uneven and depends on accidents of geography and hospital ownership. <https://goo.gl/nf2me0>
  1. ‘America’s Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,’ Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. <https://goo.gl/6dBmHF>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *KAISER HEALTH NEWS* | Online – 16 February 2017 – ‘**Right-to-die fight hits national stage.**’ Opponents of aid-in-dying laws are claiming a small victory. They won the attention of Congress this week in their battle to stop a growing movement that allows terminally ill patients to get doctors’ prescriptions to end their lives. The Republican-led effort on Capitol Hill to overturn the District of Columbia’s aid-in-dying law died Friday. But advocates worry the campaign will catalyze a broader effort to fully ban the practice, which is legal in six states and being considered in 22 more. <https://goo.gl/vZGDjv>
- WASHINGTON DC | Reuters – 13 February 2017 – ‘**U.S. Representatives vote against DC assisted suicide law.**’ The U.S. House of Representatives’ Oversight Committee voted ... to strike down a Washington DC law that would allow physician-assisted suicide there. City leaders passed legislation in December that allows terminally ill patients to end their lives with a doctor’s help, but the U.S. Constitution gives Congress the power to overturn laws in the 68-square-mile district. After hearing arguments from more than a dozen lawmakers, the committee voted 22 to 14 against the law. Overturning a DC law requires passage by both the House and Senate and signature by the president. It has happened only a handful of times since the city gained self governance. <https://goo.gl/Vh3w5F>

### [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.

### [Distribution](#)

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### [Links to Sources](#)

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

### [Something Missed or Overlooked?](#)

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

## International

### Armenia's new strategy to help those in pain

ARMENIA | Human Rights Watch – 16 February 2017 – About 8,000 people die from cancer in Armenia every year, many spending their last days in excruciating pain. But Armenia is taking an important step towards ending their suffering, and the government recently adopted a national strategy to introduce palliative care (PC) services... The strategy specifies reforms in policy, education, and medicines' availability, and designates the responsible state institutions. When curative treatment is no longer effective, patients with advanced cancer in Armenia are simply sent home. Abandoned by the health care system at arguably the most vulnerable time of their lives, people with life-limiting illnesses face pain, fear, and anguish without professional support. The support they need is PC. Morphine, the mainstay medication for treating severe pain, is inexpensive and easy to administer, but fewer than 3% of those who need morphine in Armenia get it. That's because the government has put in place nearly insurmountable bureaucratic barriers around the prescribing and dispensing of morphine. The Armenian government has long recognized the need for PC, but regrettably it has taken officials over three years to develop and adopt the strategy and action plan. The

strategy recognizes the need to amend regulations restricting access to pain relief medications, and the government plans to review them in 2018. <https://goo.gl/qxiDSY>



### Specialist Publications

'What is the value of palliative care provision in low-resource settings?' (p.8), in *BMJ Global Health*.

Noted in Media Watch 20 July 2015, #419 (p.8):

- ARMENIA | Human Rights Watch – 13 July 2015 – '**Armenia: Needless pain at end of life.**' Thousands of patients with advanced cancer in Armenia suffer from avoidable, severe pain every year because they cannot get adequate pain medications.<sup>1</sup> A new report documents the overall lack of palliative care (PC) services in Armenia and the government's overly restrictive regulations for getting strong pain medication. It also describes ingrained practices among healthcare professionals that impede adequate pain relief, and the lack of training and education of healthcare professionals in (PC). <https://goo.gl/nFRc42>

1. 'Cancer and the Struggle for Palliative Care in Armenia,' Human Rights Watch, July 2015. <https://goo.gl/Skqrw5>



### 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>

## China issues first end-of-life care standards

CHINA | Sixth Tone (Shanghai) – 16 February 2017 – Thirty years after China's first hospice center opened its doors in Beijing, the country's top health authority has finally released a set of standards for palliative care... The new rules, issued by the National Health & Family Planning Commission in late January specify that such facilities should be equipped with at least 50 beds and that there should be at least one doctor, four nurses and 12 caregivers for every 10 beds. China's end-of-life health care is desperately under resourced. In a country where 7 million people die each year, there are just 2,103 hospices and 289 nursing homes for dedicated palliative services – those which provide termi-

nally ill patients with day-to-day care, psychological support, and physical pain relief – according to a 2015 report by state news agency Xinhua. <https://goo.gl/iGyO7m>

### Specialist Publications

**'Knowledge, attitudes, and preferences of advance decisions, end-of-life care, and place of care and death in Hong Kong: A population-based telephone survey of 1,067 adults'** (p.14), in *Journal of Post Acute & Long Term Care Medicine*.

**N.B.** Link to the National Health & Family Planning Commission's report: <https://goo.gl/uGDxzc> China was ranked 71 of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World.' Published in 2015 by The Economist Intelligence Unit, the index was commissioned by the Lien Foundation of Singapore. [Noted in Media Watch 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5>

Noted in Media Watch 4 April 2016, #456 (p.13):

- *THE LANCET*, 2016;387(10025):1272. **'Barriers in palliative care in China.'** The country's ranking in the '2015 Quality of Death Index' is very worrying, and we recognise that some barriers do exist in the development of palliative care (PC) in China. First, most Chinese people believe that only dying patients need PC. Affected by the traditional view that people with terminal illnesses have short life expectancies, patients and their families become desperate and find it difficult to accept PC emotionally. Second, financial cost and the absence of national strategies and guidelines are major problems. Third, the shortage of professional PC staff is severe. <http://goo.gl/Q1i0cD>

## End-of-life care in Australia

### 24-hour palliative care only available to parts of Lake Macquarie

AUSTRALIA (New South Wales) | *The Newcastle Herald* – 14 February 2017 – Lake Macquarie residents living south of the Fennell Bay bridge do not receive the same 24-hour palliative care services as their northern neighbours, and instead have to rely on a telephone service for care outside of business hours. Lake Macquarie Member of Parliament Greg Piper revealed in parliament ... that he had been advised by the government that residents in highly populated areas like Toronto and Morisset do not have access to the same 24-hour care as other parts of Lake Macquarie. Mr. Piper read out advice he'd received from new health minister Brad Hazzard's office that the Westlakes Community Health Service – which operates south of Fennell Bay and Swansea down to Wyee – provides a "24-hour on-call service to provide advice and support to patients" but that after business hours that service was provided by

telephone. Mr. Piper said the difference in service created a "them and us" situation in Lake Macquarie. "In my electorate of Lake Macquarie I fear that services are actually being eroded rather than promoted and expanded," he said. <https://goo.gl/mFYz8J>

### Specialist Publications

**'Access to palliative care services during the terminal hospital episode reduces intervention rates and hospital costs: A database study of 19,707 elderly patients dying in hospital, 2011-2015'** (p.12), in *Internal Medicine Journal*.

**'The impact of community-based palliative care on utilization and cost of acute care hospital services in the last year of life'** (p.12), in *Journal of Palliative Medicine*

## End-of-life care in Italy

### **Palliative sedation for terminal ALS man**

ITALY | Agenzia Nazionale Stampa Associata (Roma) – 14 February 2017 – A terminal ALS patient has asked for and been given palliative sedation until death in the first case of its kind in Italy... Dino Bettamin, a butcher from Montebelluna near Treviso, died on Monday aged 70. <https://goo.gl/O8tEwH>

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

Noted in Media Watch 25 January 2016, #446 (p.16):

- *RECENTI PROGRESSI IN MEDICINA*, 2015;106(12):593-596. **“Dignity” at the end of life: Ethical and deontologic reflections.** In Article 32 of the Italian Constitution, the concept of dignity is taken into account when stating the autonomy of the individual decision-making about health treatment. This is confirmed by the Code of Medical Ethics (2014): the right to self-determination and the right of patients to decide for themselves in accordance with their own life plans, are at the core of the concept of “human dignity.” <http://goo.gl/CKwQqB>

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

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | *The Australasian* (Melbourne) – 18 February 2017 – **‘Government’s advisers look at “time to live” curb on assisted suicide.** Victoria’s euthanasia legislation will depart from a model proposed by a parliamentary inquiry, with the government’s advisers considering a specific upper limit on the time patients are diagnosed to live before assisted suicide is permitted. The “time to live” option being considered by a special taskforce advising the government on the euthanasia legislation contrasts with an ambiguous recommendation from the Inquiry into End-of-Life Choices that people should qualify for assisted suicide in their final “weeks or months.” <https://goo.gl/m4X2fo>
- MALTA | *Malta Today* (San Gwann) – 15 February 2017 – **‘Medical council against euthanasia: “We don’t want youths euthanising their grandparents.”** The Malta Medical Council has come out strongly against euthanasia, telling MPs that it cannot even be considered an option for patients in extreme states of suffering. The Council was invited to address a joint parliamentary committee debating euthanasia, that will now draft a report after hearing several witnesses. At the end of the session, government Whip Godfrey Farrugia and Opposition MP Robert Cutajar both confirmed that their respective parties are fully opposed to euthanasia. <https://goo.gl/3EEfCC>

## Specialist Publications

### **Provider perspectives on advance care planning documentation in the electronic health record: The experience of primary care providers and specialists using advance health-care directives and Physician Orders for Life-Sustaining Treatment**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 February 2017 – The authors’ findings imply the need for improved interoperability between hospital and outpatient electronic health records systems, consensus about which providers should document advance care planning (ACP), and widespread standardized clinic workflows for ACP. A recent Hartford Foundation poll of 736 physicians found ACP was a “conversation stopper”; only 29% of physicians were trained in ACP communication, 46% frequently or sometimes felt unsure what to say, and only 29% said their health-care system had a formal system for ACP.<sup>1</sup> The providers the authors interviewed were not unsure what to say in these conversations, although they may be unaware of communication problems. However, they desired standardized workflows so that all providers have the same expectations about who should lead ACP conversations and when, and where and how to document ACP to ensure patients’ wishes are honored. <https://goo.gl/jtWCrH>

Cont.

1. 'Conversation Stopper: What's preventing physicians from talking with patients about end of life and advance care planning?' John A. Hartford Foundation, California Health Care Foundation & Cambia Health Foundation, April 2016. [Noted in Media Watch 18 April 2016, #458 (p.3)] <http://goo.gl/NTzOpZ>

### **Multidisciplinary training on spiritual care for patients in palliative care trajectories improves the attitudes and competencies of hospital medical staff: Results of a quasi-experimental study**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 February 2017 – In this study, the authors found that a practical and concise training program on spiritual care (SC) in palliative care (PC) for health-care professionals in teaching hospitals can have a positive effect on staff attitudes and competencies, improved attention to the spiritual dimension, and temporarily can decrease barriers to SC for nurses. Training hospital had positive effects on both nurses and physicians. The authors collected data from 124 health-care professionals... As preparation for the training, nurses seem to favor reading literature, physicians preferred to check the project Web site containing additional material and videos. The trainers were evaluated positively by both nurses and physicians, scoring 3.7-4.1 on a scale from 1 to 5, on different aspects, such as knowledge, presentation, and interaction with participants and handling questions. Physicians had prepared a case presentation less often. Nurses were more satisfied with the interaction between the participants during the first lesson. <https://goo.gl/VLkibr>

Noted in Media Watch 2 January 2017, #493 (p.19):

- *MEDSCAPE* | Online – 20 December 2016 – '**A training program for spiritual care.**' Those in the field of palliative care (PC) have voiced significant concerns in recent years about workforce shortages, including a dearth of specialists, and the need to train generalists to meet a burgeoning need for providers. Almost all of this literature has been related to specialist PC physician shortages, but a recent article makes an important contribution to the literature by sharing an example of training to prepare interprofessional clinicians as generalists in spiritual care.<sup>1</sup> <https://goo.gl/7E47ZH>

1. 'Efficacy of training interprofessional spiritual care generalists,' *Journal of Palliative Medicine*, 2016; 19(8):814-821. <https://goo.gl/wMgyza>

### **What is the value of palliative care provision in low-resource settings?**

*BMJ GLOBAL HEALTH* | Online – 14 February 2017 – Palliative care (PC) is a human right, yet there are significant disparities in the worldwide provision of PC services for individuals with life-limiting illness. Of the 40 million people globally in need of PC, just 14% receive it, largely in high-income countries. While proven to be "cost-effective" in high-income settings based on principles of cost avoidance, the costs of illness for incurable disease in low-resource settings is largely unknown. The critical absence of PC services in low-resource settings results in significant costs being absorbed by the individual, family and local community. This results in intractable, devastating and perpetuating financial losses that are passed on to future generations and function as a catalyst in the poverty cycle while stunting local economic growth. In considering the direct, indirect and broader societal costs of incurable disease in low-resource countries, PC should be considered as a poverty-reduction strategy. <https://goo.gl/nMsgQu>

Noted in Media Watch 23 March 2015, #402 (p.9):

- *THE LANCET* | Online – 8 March 2015 – '**The Harvard Global Equity Initiative: Lancet Commission on global access to pain control and palliative care.**' In low-income and middle-income countries regulations hampering opioid accessibility, combined with the scarcity of trained doctors and other health professionals, has stymied delivery of pain treatment and palliative care. <https://goo.gl/CBL35I>

## Systematic review of the effectiveness, barriers and facilitators to general practitioner engagement with specialist secondary services in integrated palliative care

*BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 14 February 2017 – The general practitioner (GP) has a critical role in an integrated model of palliative care (PC) as they often know the patient and carer well, are experts in generalist care and have knowledge of health and social services in the community. Specialist palliative services have insufficient capacity to meet demand and those with non-cancer terminal conditions and those from rural and remote areas are underserved. Research has focused on improving access to PC by engaging the GP with specialist secondary services in integrated PC. Results 17 studies were included in this review. There is some evidence that integrated PC can reduce hospitalisations and maintain functional status. There are substantial barriers to providing integrated care. Principles and facilitators of the provision of integrated PC are discussed. This is an emerging field and further research is required assessing the effectiveness of different models of integrated PC. <https://goo.gl/jE4nNm>

Noted in Media Watch 6 February 2017, #498 (p.15):

- *PLOS ONE* | Online – 1 February 2017 – ‘**General practitioners’ attitudes towards essential competencies in end-of-life care: A cross-sectional survey.**’ Ninety-nine percent of GPs [i.e., survey respondents] considered the recognition and treatment of pain as important; 86% felt confident about it. Few GPs felt confident in cultural (16%), spiritual (38%) and legal end-of-life competencies, such as responding to patients seeking assisted suicide (35%), although more than half of the respondents regarded these competencies as important. Most frequent reasons to refer terminally ill patients to a specialist were lack of time (30%), better training of specialists (23%), and EoLC being incompatible with other duties (19%). <https://goo.gl/zdU4n3>

Noted in Media Watch 12 September 2016, #479 (p.10):

- *FAMILY PRACTICE* | Online – 1 September 2016 – ‘**Interprofessional communication between oncologic specialists and general practitioners on end-of-life issues needs improvement.**’ Timely end-of-life (EOL) discussions between patients and physicians are considered essential for high-quality EOL care, but research shows that these discussions frequently do not occur or occur late. In oncology, one barrier for timely EOL discussions is poor collaboration between oncologic specialists and GPs. <http://goo.gl/huZl6x>

## Palliative care discussions in multiple system atrophy: A retrospective review

*CANADIAN JOURNAL OF NEUROLOGICAL SCIENCES* | Online – 7 February 2017 – Multiple system atrophy (MSA) is an incurable neurodegenerative illness in which progressive symptoms, including stridor and acute laryngeal obstruction, occur. Advanced care planning and palliative care (PC) discussions in people living with MSA are not well defined. A total of 22 patients with MSA were included in this study. The most common symptoms were Parkinsonism, orthostatic hypotension, GI/GU dysfunction, ataxia and gait impairment. Six patients had stridor. Of the PC discussions that took place, the most common topics were diagnosis, symptoms or symptom management, and prognosis. In the majority of patients who died and who had a do-not-attempt-resuscitation order, discussions surrounding resuscitation and goals of care took place only hours before death. The authors propose a framework to guide advanced care planning and PC discussions in MSA. <https://goo.gl/CfKBRQ>



**N.B.** Additional articles on palliative care for people living with a neurological disease are noted in past issues of Media Watch, e.g., 3 October 2016, #482 (pp.9-10), and 16 May 2016, #462 (p.8).



### 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.

## **The experiences of oncology and palliative care nurses when supporting parents who have cancer and dependent children**

*CANCER NURSING* | Inprint – Accessed 14 February 2017 – This study explored the experience, needs and confidence of nurses working in acute cancer services when supporting parents with cancer who have dependent children. Nurses [i.e., study participants] described how they identified with their patients as a parent themselves. This identification with patients added to the emotionally charged context of care and resulted in nurse avoidance of the troubling issue of dependent children. Nurses identified the importance of peer support with regular opportunities to reflect on practice when dealing with issues relevant to parents and children. Oncology and palliative care nurses take a reactive approach to family centred care, taking their cue from patients to initiate or request support for their children. Guidance was needed on children's developmental stages and how to communicate with children of different ages. Additionally, guidance was needed on assessing family needs and access to up to date resources. To enable nurses to engage with the issue of children, strategies of peer support and further educational opportunities need to be implemented. <https://goo.gl/deQ435>

### **Related**

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 13 February 2017 – '**Fathers raising motherless children: Widowed men give voice to their lived experiences.**' Little is known about the experiences of widowed men with dependent children. With such limited knowledge it is not clear how mental health professionals can assist this population. In this qualitative case study the researcher describes the experiences of ten widowed fathers from the South-eastern U.S. as they struggle with their new parenting responsibilities after the death of their wives and their children's mothers. The interview data revealed three themes: 1) Ways to cope; 2) Concerns; and, 3) Newfound respect. These themes and their sub-categories are presented together with suggestions on how to assist widowers with dependent children. <https://goo.gl/HG42MW>

### **Children's Project on Palliative/Hospice Services**

#### **Palliative sedation for intractable suffering at the end of life in children**

*CHIPPS E-JOURNAL* | Online – February 2017 Issue – Every year in the U.S., there are close to 19,000 pediatric deaths age 1-19 years, many of them from chronic complex conditions such as malignant, neuromuscular, and cardiovascular conditions. In any given day an estimated 5,000 of these children are in their last 6 months of life. For many, attentive pain and symptom management is successful. But parents report over ¾ of their children "suffered a lot" at end of life especially from pain, fatigue, gastrointestinal issues, and poor appetite. Skilled pediatric palliative care supports excellent pain and symptom management for most children with goals of comfort and optimal interaction. Palliative sedation (PS) addresses a small percent of these whose pain and symptoms are refractory to optimal management and are causing intolerable suffering. Unfortunately, there are few data describing the number of cases per year and appropriate guidelines for PS in children and adolescents. Much of the experience and many of the recommendations are based on adults. <https://goo.gl/1MKW8S>

**N.B.** Scroll down to p.34 in the February issue of the journal.

Noted in Media Watch 4 June 2016, #443 (p.10):

- *MÉDECINE PALLIATIVE* | Online – 29 December 2015 – '**Palliative sedation in pediatric patients: Guidelines established by the pediatric palliative consultation service at Sainte-Justine hospital, Montréal, Québec.**' Recommended criteria: 1) Ensure symptoms are really refractory; 2) Conduct an interdisciplinary meeting; 3) Conduct a meeting with the family (and patient if he/she is apt); and, 4) Decide on type and level of sedation. Adequate monitoring and comfort care should be provided at all times to the patient. Assistance and support of family is paramount throughout the decision-making process and course of sedation. Palliative sedation must be supervised by medical and pharmacological guidelines and an institutional policy. <http://goo.gl/B7XOFq>

**N.B.** French language article.

Cont.

Noted in Media Watch 12 October 2015, #431 (p.14):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 October 2015 – ‘**Pediatrician ambiguity in understanding palliative sedation at the end of life.**’ Pediatricians [i.e., survey respondents] were concerned with a decreased level of consciousness as the goal of palliative sedation (PS). They were split on whether they view PS as a distinct entity or as one broad continuum of care, equivalent to aggressive symptom management. Institutional-based policies are essential to clarify acceptable practice, enable open communication, promote further research. <http://goo.gl/7OZtA6>

### Missing life stories

#### **The narratives of palliative patients, parents and physicians in paediatric oncology**

*EUROPEAN JOURNAL OF CANCER CARE* | Online – 8 February 2017 – This paper aims to provide insight into how children, parents and physicians make sense of progressive childhood cancer. It also explores how this meaning-giving process interacts with cultural dominant stories on cancer and dying. The presented data come from 16 open-ended, face-to-face interviews with palliative paediatric patients, their parents and physicians. Quest narratives were relatively rare compared to both chaos and restitution stories. All participants welcomed chaos stories as a liminal haven between quest and restitution. The possibility that the child could die was either ignored or briefly contemplated, but then immediately pushed away. Except for one patient, children never directly addressed the topic of death. The way in which death was presented raises important questions about how the social discourse on dying is framed in terms of choice, autonomy and individuality. This discourse not only determines the way in which children and adults relate to the minor’s death, it also constitutes an obstacle to children’s participation in decision-making. <https://goo.gl/6gtzKs>

Noted in Media Watch 27 April 2015, #407 (p.11):

- *HEALTH PSYCHOLOGY*, 2015;34(4):446-452. ‘**The parents’ ability to attend to the “voice of their child” with incurable cancer during the palliative phase.**’ Whether or not the voice of children approaching the end-of-life is heard often depends on their parents’ ability to give them a voice. Professional caregivers have a difficult task in supporting parents in giving their child his or her voice, while at the same time preserving their – and their parents’ – ability to cope. <http://goo.gl/fSgXw5>

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

#### **How can we increase the use of palliative care in Medicare?**

*HEALTH AFFAIRS* | Online – 13 February 2017 – Medicare will cover some elements of palliative care (PC), but payments are generally less than the cost of delivering the service because Medicare’s approach to reimbursement values procedures over time spent with patients and families. Hospitals have begun investing in PC teams because of the acute disease burden their patients experience near the end of life, but the availability of such care varies widely. Increasing the system-wide use of PC will require a new payment approach for Medicare, the insurer for over eight in 10 decedents annually in the U.S. This article describes a community-based, interdisciplinary PC model that spans care settings and is being evaluated in a Center for Medicare & Medicaid Innovation (CMMI) demonstration project. It provides some early lessons on how alternative payment models for PC might be developed to increase its provision in Medicare. <https://goo.gl/KtcF60>

## End-of-life care in Australia

### **Access to palliative care services during the terminal hospital episode reduces intervention rates and hospital costs: A database study of 19,707 elderly patients dying in hospital, 2011-2015**

*INTERNAL MEDICINE JOURNAL* | Online – 14 February 2017 – This study examines cost savings associated with access to palliative care (PC) during the hospital episode ending in death for a large sample of elderly patients. Access to PC service was reported for 33.2% of patients, 59.5% for those with a cancer diagnosis, and 24.3 % for other patients. Rates were significantly lower in private hospitals for all patient groups. For the complete sample, PC access was associated with significantly lower rates of admission into ICU, fewer coded procedures and lower costs for hospital accommodation, medical and diagnostic services. Mean total cost for terminal episodes was \$10,801 for PC patients and \$16,165 for those with no recorded PC access. All differences remained significant after adjustment for patient age, co-morbidity and hospital type. <https://goo.gl/uujHvy>

#### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 February 2017 – ‘**The impact of community-based palliative care on utilization and cost of acute care hospital services in the last year of life.**’ Decedents who accessed a community-based palliative care service had triple the odds of dying out of hospital compared with those who did not. Unplanned hospitalizations were reduced in the last year and last week of life, as were emergency department presentations in the last year and last week of life, respectively. There were significant reductions in average total bed days and acute care costs over the last year of life. <https://goo.gl/kWZeCa>

### **A framework of comfort for practice: An integrative review identifying the multiple influences on patients’ experience of comfort in healthcare settings**

*INTERNATIONAL JOURNAL FOR QUALITY IN HEALTH CARE* | Online – Accessed 16 February 2017 – This review aims to develop a framework representing patients’ complex perspective of comfort to inform practice and guide initiatives to improve the quality of healthcare. Sixty-two studies (14 theoretical and 48 qualitative) were included. Qualitative studies explored patient and staff perspectives in varying healthcare settings including hospice, emergency departments, paediatric, medical and surgical wards and residential care for the elderly. From patients’ perspective, comfort is multidimensional, characterized by relief from physical discomfort and feeling positive and strengthened in one’s ability to cope with the challenges of illness, injury and disability. Different factors are important to different individuals. The authors identified 10 areas of influence within four interrelated levels: 1) Patients’ use of self-comforting strategies; 2) Family presence; 3) Staff actions and behaviours; and, 4) Environmental factors. The authors provide new insights into the nature of comfort as a highly personal and contextual experience influenced in different individuals by different factors that they have classified into a framework to guide practice and quality improvement initiatives. <https://goo.gl/dF5YAI>

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

- *BMC PALLIATIVE CARE* | Online – 2 August 2016 – ‘**Comfort experience in palliative care: A phenomenological study.**’ This study demonstrated that the palliative care unit can be perceived as a space of comfort where the patient finds a suitable therapeutic context to their needs, but also as a place of discomfort where the patient is confronted with its vulnerability. <http://goo.gl/FX0Xh9>

Noted in Media Watch 28 December 2015, #442 (p.8):

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2015;373 (26):2549-2561. ‘**Comfort care for patients dying in the hospital.**’ The term “comfort care” is used to describe a set of the most basic palliative care interventions that provide immediate relief of symptoms in a patient who is very close to death. Typically, these measures are used to achieve comfort for the patient rapidly. <https://goo.gl/r6fti4>

## Cross-border investment in palliative care

*THE IRISH MEDICAL TIMES* | Online – 17 February 2017 – Health agencies on the island of Ireland have announced a joint cross-border three-year investment in the future of palliative care research worth €210,000. The investment has been made to the Palliative Care Research Network, an all-island entity housed within the All Ireland Institute of Hospice & Palliative Care. The funding provided by the Health Research Board in the Republic and Health & Social Care, Research & Development Division, Public Health Agency in Northern Ireland will support the recruitment of additional staff to manage research in the sector and maximise knowledge transfer of findings into policy and practice. <https://goo.gl/N0Srr9>



All Ireland Institute of  
Hospice and Palliative Care

Noted in Media Watch 13 June 2016, #466 (p.9):

- IRELAND | *The Journal* (Dublin) – 6 June 2016 – ‘**Palliative care patient “was left groaning in pain before death.”**’ A new report has found that some patients in palliative care (PC) are being left in pain, while one family said trying to find out what services are available is like “dealing with the mafia.”<sup>1</sup> The report found that 52% of PC users said they felt frustrated or helpless during the process. The survey includes the experiences of 528 PC service users and carers from across the island (419 in the Republic of Ireland and 109 in Northern Ireland). <http://goo.gl/hWtCi9>

1. ‘Let’s Talk About Palliative Care Survey Report,’ All Ireland Institute of Hospice & Palliative Care, April 2016. <http://goo.gl/5wz471>

## Using the surprise question to identify those with unmet palliative care needs in emergency and inpatient settings: What do clinicians think?

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 February 2017 – The surprise question (SQ), “Would you be surprised if this patient died within the next year?” is effective in identifying end-stage renal disease and cancer patients at high risk of death and therefore potentially unmet palliative care needs. Following implementation of the SQ in their acute care setting, the authors sought to explore hospital-based providers’ perceptions of the tool. A total of 111/203 (55%) medical providers participated in a survey: 48/57 (84%) emergency physicians (EPs) and 63/146 (43%) inpatient providers (IPs). Most reported no difficulty using the SQ. Modest numbers in both groups reported that the SQ influenced care delivery (EPs 37%, IPs 42%) as well as goals of care (EPs 45%, IPs 52%). At least some advance care planning discussions were prompted by the SQ (EPs 45%, IPs 58%). Team discussions were influenced by SQ use for more than half of each group. Most respondents (55%) expressed some concern that their SQ responses could be inaccurate. <https://goo.gl/cjh58n>

Noted in Media Watch 1 September 2014, #373 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 28 August 2014 – ‘**A qualitative study exploring use of the surprise question in the care of older people: Perceptions of general practitioners and challenges for practice.**’ Data discussing 22 clinical cases revealed the difficulties experienced by GPs when assessing prognosis for older people with non-malignant conditions, despite their recognition of multiple mortality risk factors and high symptom burden. GPs did not appear to include the surprise question within their usual practice and expressed concerns regarding its use to facilitate discussion of advance care plans. <https://goo.gl/NhXS72>

## “She would be flailing around distressed”: The critical role of home-based palliative care for patients with advanced cancer

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 February 2017 – The authors describe findings of a pilot project in home-based palliative care, Community Bridges (CB), for patients with advanced cancer. Seventeen patients were seen. Baseline patient symptom burden and caregiver burden were high. Half of patients died within six months of enrollment. Patients and caregivers reported high program satisfaction and that CBs filled a gap in care. CB providers often served in the role as crisis managers and as trusted reporters for treating oncologists. <https://goo.gl/4iUUrv>

## Knowledge, attitudes, and preferences of advance decisions, end-of-life care, and place of care and death in Hong Kong: A population-based telephone survey of 1,067 adults

*JOURNAL OF POST ACUTE & LONG TERM CARE MEDICINE* | Online – 14 February 2017 – This is the first population-representative survey of the general Hong Kong adult population on the knowledge, attitude, and preferences of advance directives (AD), end-of-life care (EoLC), and place of care/death. A total of 85.7% [of respondents] had not heard of advance directives (AD), but 60.9% would prefer to make their own AD if legislated after explanation; and, for those who did not prefer to have an AD, the predominant concern was the possible change of mind afterward. Female participants were less willing to make an AD, whereas those with prior knowledge of do-not-attempt-cardiopulmonary-resuscitation significantly increased the chance of making an AD. In terms of life-sustaining treatments, a predominant 87.6% preferred to receive appropriate palliative care (PC) that gives comfort rather than to prolong life if being diagnosed to be terminally ill; 43% disagreed that doctors should generally try to keep patients alive for as long as possible; and, 86.2% agreed that the patient's own wishes should determine what treatment he/she should receive. PC was more preferred by age groups 50 years or above, but was less preferred by those who did not care for their family members with chronic diseases. Regarding place of death, 31.2% of the participants would choose to die at home, and among those 19.5% would still prefer to die at home even if they did not have sufficient support. The main implication of this study is that preferences to have autonomy over own EoLC, to receive PC, and to die at home were greater than the actual practice currently, highlighting the service gaps for better EoLC in the future. <https://goo.gl/UHHBqm>



**N.B.** Additional articles on end-of-life care in Hong Kong are noted in Media Watch 9 January 2017, #494 (p.7). The autonomous territory was ranked 22 of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World.' Published in 2015 by The Economist Intelligence Unit, the index was commissioned by the Lien Foundation of Singapore. [Noted in Media Watch 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5>

## Patient reluctance to discuss pain: Understanding stoicism, stigma, and other contributing factors

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 15 February 2017 – Some patients are hesitant to disclose when they are experiencing pain. However, the reasons for this, such as stoicism and concern about being a bother to others, are poorly understood. If patient pain goes unrecognized during clinical encounters, patients may also be at greater risk for pain-related crises, use of hospice/palliative care on-call services, and in-patient transfers. The authors used a review of the available evidence to better understand the various factors that contribute to an unwillingness to disclose one's pain, create a conceptual model, and identify relevant assessment measures that may be useful to practitioners. Their review identified six primary attitudes and beliefs that contribute to patient reluctance to openly admit pain: 1) Stigma; 2) Stoicism; 3) Cautiousness; 4) Fatalism; 5) Bother; and, 6) Denial. Four assessment measures that address elements of barriers to pain-related communication and four measures of non-verbal signs of pain were also identified and reviewed. <https://goo.gl/tzLd2l>

### Related

- *PATIENT EDUCATION & COUNSELING* | Online – 16 February 2017 – '**Promoting patient participation in healthcare interactions through communication skills training: A systematic review.**' Most [studies reviewed] targeted primary care or cancer patients and used a randomized controlled study design. Interventions used a variety of training formats and modes of delivering educational material. Reported findings suggest that communication training is an effective approach to increase patients' total level of active participation in healthcare interactions and that some communication behaviors may be more amenable to training (e.g., expressing concerns). <https://goo.gl/FWWLWd>

## **Discontinuation of potentially inappropriate medications at the end of life: Perspectives from patients, their relatives, and physicians**

*NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE* (Netherlands Journal of Medicine) | Online – Accessed 14 February 2017 – Patients and their relatives [i.e., study participants] are prepared to discontinue potentially inappropriate medications (PIMs). Still, some reported that stopping might give them the feeling that their attending physician has already thrown in the towel. [Participating] physicians mentioned several reasons for not ceasing PIMs: cessation not considered, low priority, and unknown consequences of discontinuation. Some physicians were concerned that discussing the discontinuation of PIMs with patients could make patients acutely aware of the approach of death, and give patients the impression that they are receiving inferior medical care. If physicians communicate with patients the possibility of discontinuing medications, they seem to emphasize the clinical futility of continuing PIMs in light of the patient's limited life expectancy. <https://goo.gl/16HFAf>

**N.B.** Dutch language article.

### **Related**

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 February 2017 – ‘**Use of preventive medication in patients with limited life expectancy: A systematic review.**’ Patients continue to receive medications that are not prescribed as symptomatic treatment despite having a limited life expectancy. Very few rigorous studies have been conducted on minimising preventive medications in patients with limited life expectancy and expert opinion varies on medication optimisation at the end of life. <https://goo.gl/ZL4XZn>

Noted in Media Watch 4 April 2016, #456 (p.11):

- *HOME HEALTHCARE NOW*, 2016;34(4):228-229. ‘**It’s time to talk: Starting a conversation about discontinuing medications at end of life.**’ Although considerable attention is being paid to medication reconciliation ... little attention has been paid to developing systematic approaches to stopping medications at transitions of care, particularly for patients near the end of life. In hospice, helping patients reduce the number of medications may help to improve patient’s quality of life and reduce medication-related side effects. <http://goo.gl/YIn21x>

Noted in Media Watch 11 January 2016, #444 (p.9):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 5 January 2016 – ‘**Inappropriate prescribing of preventative medication in patients with life-limiting illness: A systematic review.**’ The way in which preventative medication appropriateness is assessed in patients with life-limiting illness varies considerably – with some methodologies utilising criteria previously developed for elderly populations. Given this lack of standardisation, improving the prescribing in this context requires an approach specifically designed and validated for populations with life-limiting illness. <http://goo.gl/rhYmzW>

## **Cautioning health-care professionals: Bereaved persons are misguided through the stages of grief**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 13 February 2017 – Science and practice seem deeply stuck in the so-called stage theory of grief. Health-care professionals continue to “prescribe” stages. Basically, this perspective endorses the idea that bereaved people go through a set pattern of specific reactions over time following the death of a loved one. It has frequently been interpreted prescriptively, as a progression that bereaved persons must follow in order to adapt to loss. It is of paramount importance to assess stage theory, not least in view of the current status of the maladaptive “persistent complex bereavement-related disorder” as a category for further research in *Diagnostic and Statistical Manual of Mental Disorders*. The authors, therefore, review the status and value of this approach. It has remained hugely influential among researchers as well as practitioners across recent decades, but there

Cont.

has also been forceful opposition. Major concerns include the absence of sound empirical evidence, conceptual clarity, or explanatory potential. It lacks practical utility for the design or allocation of treatment services, and it does not help identification of those at risk or with complications in the grieving process. Most disturbingly, the expectation that bereaved persons will, even should, go through stages of grieving can be harmful to those who do not. <https://goo.gl/VX6IUz>

Noted in Media Watch 25 May 2015, #411 (p.10):

- *ILLNESS, CRISIS & LOSS* | Online – 21 May 2015 – **‘Let’s stop “staging” persons who are coping with loss.’** This article offers a critical analysis of Elisabeth Kübler-Ross and David Kessler’s *On Grief & Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*. Although the five stages of grief are described in Chapter 1, they play little role thereafter. Further, readers are told these stages are neither universal nor linear. Consequently, it would be desirable to stop staging persons who are coping with loss or at least be extremely cautious in using this stage-based model in appreciating their unique journeys. <https://goo.gl/rlBicG>

### **The use of Quality-Adjusted Life Years in cost-effectiveness analyses in palliative care: Mapping the debate through an integrative review**

*PALLIATIVE MEDICINE* | Online – 13 February 2017 – There is an ongoing debate concerning the appropriateness of Quality-Adjusted Life Years (QALYs) for decision-making in palliative care (PC). Three themes regarding the pros and cons were identified [in this review]: 1) Restrictions in life years gained; 2) Conceptualization of quality of life and its measurement, including suggestions to adapt this; and, 3) Valuation and additivity of time, referring to changing valuation of time. QALYs might be more valuable for PC if specific issues are taken into account. Despite restrictions in life years gained, QALYs can be achieved in PC. However, in measuring quality of life, the authors recommend to ... make use of quality of life or capability instruments specifically for PC. <https://goo.gl/9Bldil>

Noted in Media Watch 11 August 2014, #370 (p.17):

- *JOURNAL OF MEDICAL ETHICS* | Online – 31 July 2014 – **‘Quality-adjusted life year, euthanasia, and the puzzle of death.’** This paper considers the problems that arise when death, a philosophically difficult concept, is incorporated into healthcare metrics, such as quality-adjusted life years (QALYs). These problems relate closely to the debate over assisted suicide because negative QALYs scores can be taken to mean that patients would be “better off dead.” <https://goo.gl/TdYCzX>

### **Understanding meaning in life interventions in patients with advanced disease: A systematic review and realist synthesis**

*PALLIATIVE MEDICINE* | Online – 13 February 2017 – This review offers an exhaustive analysis of all the published meaning in life (MiL) interventions that have been implemented to date in patients with advanced disease. Despite increasing interest over the last decade, the number of interventions designed specifically to enhance MiL among end-of-life (EoL) patients remains small. The explanatory model derived from the findings of this review may help clinicians to decide which kind of intervention is most likely to reduce patients’ suffering in a given context. As palliative care continues to develop, there is a need for new strategies that go beyond ensuring the patient’s physical comfort and emotional adjustment, which are able to prevent or lessen existential distress at the EoL. MiL interventions could play a key role in promoting well-being in this vulnerable population with complex care needs. <https://goo.gl/V95A1J>

#### **Related**

- *PATIENT RELATED OUTCOME MEASURES*, 2017;8:15-21. **‘An assessment of meaning in life-threatening illness: Development of the Healing Experience in All Life Stressors (HEALS).’** Patients with life-threatening or chronic illness report an experience of increased positive psychological, social, and/or spiritual change during diagnosis and/or treatment of their illness, even in the face of unfavorable prognosis. This transformation begins through the ability to make their life meaningful by forming meaningful connections that emerge through self-introspection and relationships with a divine entity, nature, and other people. <https://goo.gl/VjeV1i>

## Guidance on conducting and reporting Delphi studies in palliative care: Recommendations based on a methodological systematic review

*PALLIATIVE MEDICINE* | Online – 13 February 2017 – This review analysed the application of the Delphi technique for the development of best practice guidance in palliative care with a particular focus on the quality of the study conduct and the transparency of reporting. The authors recommend a rigorous use of the technique, including justification of details in the study design. Building on previous treatises, a guide for the conducting and reporting of Delphi studies was created to allow an appraisal of the methodological quality and the robustness of the resulting recommendations. Like existing standards for other types of research, this can be used by researchers, reviewers and journal editors. <https://goo.gl/iffB3ie>

### From the archives

- *SUPPORTIVE CARE IN CANCER*, 2008;16(8):935-942. ‘**Applying the Delphi process to palliative care tool development: Lessons learned.**’ The Delphi technique can facilitate national or international cooperation both asynchronously (e.g., with mail-out or electronic surveys) and synchronously (e.g., with face-to-face meetings or video conferencing). International input can assure palliative care tools are relevant in diverse clinical settings and practice cultures. <https://goo.gl/vFvKYa>

### Assisted (or facilitated) death

Representative sample of recent journal articles:

- *NURSING ETHICS*, 2017;24(1):3-8. ‘**Nursing and assisted dying: Understanding the sounds of silence.**’ Nursing has always had a strong voice in favor of people who are suffering, being present at their bedside and giving empathic care to the living and the dying, helping people to cope with the certitude of death and the uncertainty of its hour. An expression of this “natural” endeavor of nursing can be found in the preamble to the code of ethics of the International Council of Nursing, which states that “...nurses have four fundamental responsibilities: to promote health, to prevent illness, to restore health and to alleviate suffering,” and culminates in stating that “the need for nursing is universal.” This special issue of *Nursing Ethics* explores different perspectives and possible future directions of this commitment in the context of assisted dying.<sup>1</sup> <https://goo.gl/HgalHl>

1. Journal contents page: <https://goo.gl/rv8pwO>

- *PSYCHIATRIC SERVICES* | Online – 15 February 2017 – ‘**Should mental disorders be a basis for physician-assisted death?**’ Laws permitting physician-assisted death in the U.S. currently are limited to terminal conditions. Canada is considering whether to extend the practice to encompass intractable suffering caused by mental disorders, and the question inevitably will arise in the U.S. Among the problems seen in countries that have legalized assisted death for mental disorders are difficulties in assessing the disorder’s intractability and the patient’s decisional competence, and the disproportionate involvement of patients with social isolation and personality disorders. Legitimate concern exists that assisted death could serve as a substitute for creating adequate systems of mental health treatment and social support. <https://goo.gl/5tQ3to>

### Worth Repeating

#### Anger: A common form of psychological distress among patients at the end of life

*INTERNATIONAL JOURNAL OF PALLIATIVE NURSING*, 2012;18(12):592-596. Although a certain level of psychological distress such as anger is expected in terminally ill patients owing to their situation such responses may also be dysfunctional. This paper highlights the challenges and complexities of adequately assessing and supporting palliative care (PC) patients who are presenting with psychological distress in the form of anger in order to relieve their suffering and assist them in resolving their issues and improving their quality of life. Anger can be difficult to treat and for some patients can be more distressing than some physical symptoms. This paper offers anger management guidance to PC practitioners. [Noted in Media Watch 24 December 2012, #285 (p.7)] <https://goo.gl/8z3QLu>

## [Media Watch: Online](#)

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/o9wzNe>

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/5d1I9K>

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



## Closing the Gap Between Knowledge & Technology

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

<http://goo.gl/OTpc8l>

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