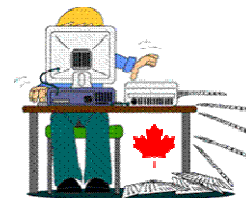


Media Watch...

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 'Forgiveness facilitation in palliative care: A scoping review protocol' (p.10), in *JBI Database of Systematic Reviews & Implementation Reports*.

Canada

Ontario falls short of hospice bed target

ONTARIO | *The Catholic Register* (Toronto) – 20 October 2017 – The Ontario government will fall 35% short of its own goal for expanding hospice access by 31 March 31 2019, *The Catholic Register* has learned. A March 2016 report to the government by the Ontario Palliative Care Network informed provincial cabinet Ontario would need 814 hospice care beds by the end of the 2018-2019 fiscal year. The actual number of beds Ontario's Ministry of Health expects to see operating at that point will be 528 – 286 short of its goal. The report was obtained by *The Catholic Register* through a Freedom of Information request. The 814 goal is itself short of international standards, said palliative care (PC) expert Dr. Jose Pereira. "For every 100,000 people you need 10 beds, on average. Of those 10, two or three of them have to be acute PC unit beds," said Pereira, the director of research with the College of Family Physicians of Canada. Given a provincial population of 13.5 million, Ontario currently needs 1,300 hospice and PC beds, of which about 900 should be lower maintenance hospice beds and the remaining 400 must be acute PC beds located in hospitals, said Pereira. The province currently has 341 hospice beds spread across the province and should have 390 in place before the end of this year, said a spokesperson for the Ministry of Health & Long Term Care. To measure how poorly Ontario is doing, Pereira compared Edmonton to Ottawa, two cities with fairly comparable populations. In the tale of two cities, Edmonton has 90 hospice beds and Ottawa 19. Edmonton has 24 acute PC hospital beds. Ottawa has 31 PC beds in hospitals, but only about half of them are really capable of taking on the complex cases that can't be cared for in a hospice, said Pereira. <https://goo.gl/wmMefd>

Noted in Media Watch 4 July 2016 (#469, p.2):

- ONTARIO | Health Quality Ontario – 28 June 2016 – '**Ontarians are talking about end-of-life care, yet for many, palliative care may begin too late or not at all, new report finds.**' Almost 60% of people in Ontario who die receive palliative care (PC) services, according to a new report by Health Quality Ontario.¹ And among those who have a record of receiving PC, about half begin to receive it in their last month of life. <http://goo.gl/4iQXTu>

1. 'Palliative Care at the End of Life,' Health Quality Ontario, June 2016. <http://goo.gl/GW0Xh9>

Cont.

Noted in Media Watch 14 March 2016 (#453, p.2):

- ONTARIO | *The Ottawa Citizen* – 11 March 2016 – **‘Numerous gaps in Ontario’s system for palliative care, report finds.’** The way Ontario’s health system cares for the dying is full of holes that need patching, Ottawa South Member of the Provincial Parliament John Fraser says in an official report the provincial government is to use as a guide to those fixes.¹ <http://goo.gl/GEFYP1>

1. ‘Palliative & End-of-Life Care Provincial Roundtable Report,’ Ontario Minister of Health & Long-Term Care, March 2016. <http://goo.gl/eRyw8K>

Health Quality Ontario

Far too many hospital beds occupied by patients who don’t need to be there: Report

ONTARIO | *The Toronto Star* – 19 October 2017 – The number of hospital beds occupied by patients who don’t need to be there and are waiting to receive health care elsewhere could fill 10 large hospitals, according to an annual report by the agency that monitors the performance of Ontario’s health system.¹ The report ... confirms that “hospital capacity” is a significant problem in the province. It reveals that in 2015-2016, an average of 3,961 Ontario hospital beds per day were occupied by patients, most of them elderly, waiting for long-term care, rehabilitation or home care. The proportion of inpatient days which hospital beds were occupied by these patients rose to 13.9% that year, up from 13.7% from the previous year. That equates to an increase of 25,000 in the number of days that hospital beds were occupied by patients who did not need to be there. When inpatient beds are full, it means

patients coming into the emergency department must wait for these to be freed up before they can be admitted. The report shows that patients spent on average 90 minutes longer in the ER this past year before being admitted to inpatient beds. <https://goo.gl/RBg64S>

Health Quality Ontario report

Chapter 9: Palliative Care

This chapter highlights results for the following common quality agenda indicators related to palliative care (PC): unplanned emergency department visits; home care services; and, home visits by a doctor. Additional results for PC indicators can be found in the Technical Data Table available on the Health Quality Ontario website: <https://goo.gl/RBg64S>

1. ‘Measuring Up 2017,’ Health Quality Ontario, October 2017. <https://goo.gl/hjBreX>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | CBC News (Winnipeg) – 20 October 2017 – **‘Number of medically assisted deaths on the rise in Manitoba.’** The number of people reaching out to the special team that delivers assisted death in Manitoba has significantly grown since July. Eighty-five people have contacted the Medical Assistance in Dying (MAiD) team from July to 10 October, with 14 receiving medically assisted deaths, according to numbers from the Winnipeg Regional Health Authority. That three-month period nearly matches the 99 people who contacted the team in all of 2016. There has been a steady increase since a Supreme Court of Canada decision threw out Canada’s laws barring physician-assisted death 6 February 2015. Following that decision, but before Bill C-14 governing medical assistance in dying passed on 17 June 2016, three Manitobans received a physician-assisted death, but it was a long process involving petitioning the court for approval. <https://goo.gl/qtamzP>



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.15.

U.S.A.

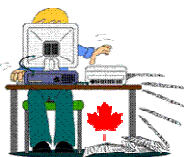
Amid for-profit surge, rural hospice has offered free care for 40 years

WASHINGTON STATE | *Kaiser Health News* – 20 October 2017 – In a nation where Medicare pays nearly \$16 billion a year for hospice care, and nearly two-thirds of providers are for-profit businesses, Volunteer Hospice of Clallam County in Port Angeles is an outlier. Since 1978, the hospice founded by Rose Crumb – a mother of 10 and devoted Catholic – has offered free end-of-life care to residents of Port Angeles and the surrounding area. She was the first in the region to care for dying AIDS patients in the early days of the epidemic. Her husband, “Red” Crumb, who died in 1984 of leukemia, was an early patient. “He died the most perfect death,” Rose Crumb told visitors on a recent afternoon. “He spent time alone with each of our kids. That meant so much to him.” At the same time, Crumb and her successors have refused to accept federal funding or private insurance, relying instead on a mostly volunteer staff and community donations to keep the hospice going. That’s rare, said Jon Radulovic, a spokesman for the National Hospice & Palliative Care Organization, a trade group. Most of the nation’s 4,000-plus hospices receive Medicare payments for their services. He estimates there are only a few volunteer hospices like Crumb’s in the U.S. There was pressure in the early years to “take the money,” as Crumb put it. But she had little use for the regulations that accompanied federal Medicare reimbursement starting in 1982. <https://goo.gl/WxdaVf>

N.B. Volunteer Hospice of Clallam County website: <https://goo.gl/P5ER7d>. Additional articles on the provision and delivery of hospice and palliative care in rural and remote regions of the U.S. are noted in the 2 October 2017 issue of Media Watch (#532, pp.3-4).

Physician-assisted suicide: Research and government reports

MASSACHUSETTS | Journalist’s Resource – 19 October 2017 –As of late 2017, physician-assisted suicide was legal in six states – Oregon, California, Vermont, Washington, Colorado and Montana – and the District of Columbia. As the “right-to-die” movement has gained traction in recent years, lawmakers nationwide have debated whether doctors should be able to prescribe life-ending drugs to patients who have months to live. In early 2017, the Hawaii Legislature voted to defer a decision on the issue. Meanwhile, legislators in Massachusetts have been considering the ‘End of Life Options Act,’ which allows certain patients to receive medication “to self-administer to bring about a peaceful death.” The topic is a contentious one, packing meetings and often pitting religious leaders who argue for the preservation of human life against patient activists who say sick adults should be able to die on their own terms. It’s important to point out that assisted suicide is different than euthanasia, although some people mistakenly use the terms interchangeably. In euthanasia, a doctor directly causes a patient’s death by administering a lethal substance. In an assisted suicide, a doctor generally prescribes or dispenses a lethal drug that the patient may ingest or administer on his or her own. Journalist’s Resource has collected government reports from some of the states that allow assisted suicide. It provides them as a resource, along with several peer-reviewed studies that look at which kinds of patients take advantage of assisted-suicide laws and how policies and trends in the U.S. compare to those in Europe. <https://goo.gl/M3EJBj>



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>

A big disconnect: New report finds many doctors and patients don't speak the same language

PENNSYLVANIA | *The Inquirer* (Philadelphia) – 19 October 2017 – It is no secret that physicians sometimes struggle to translate the language of medicine for their patients. Imagine what it's like if they literally speak different languages. A new survey¹ suggests that type of communication barrier is common in the Philadelphia area – with plenty of immigrants in both the physician and patient populations, but not necessarily from the same countries. The most common “mismatch” locally is Vietnamese, according to the analysis by Doximity, a physician social network. Among the 330,000 area residents who do not speak English very well, 5.8% speak Vietnamese, while less than 1% of local physicians speak that language. Spanish is far and away the most common non-English language spoken by both pa-

tients and physicians. The top languages spoken by doctors? They are Spanish (36.2%), Hindi (13.8%) and French (8.8%). Nearly half (44.7%) of all physicians who speak a non-English language graduated from a medical school outside of the U.S. Many of these foreign graduates are immigrants to the U.S., and the language skills they bring are important in clinical settings given the diverse languages spoken by the U.S. public, Doximity said. <https://goo.gl/z5uRHB>

Specialist Publications

'Cross-cultural differences in communication about a dying child' (p.12), in *Pediatrics*.

1. 'First National Study of Language Barriers in U.S. Health Care,' Doximity, San Francisco, California, October 2017. **Download/view report at:** <https://goo.gl/xnW4yo>

Noted in Media Watch 10 April 2017 (#507, p.13):

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – '**Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care.**' The authors present a case that generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. <https://goo.gl/thpFmR>

N.B. Additional articles on the use of interpreters in the context of end-of-life care are noted in the 20 June 2016 issue of Media Watch (#467, p.15).

International

End-of-life care in Denmark

People increasingly prefer to die at home, study shows

DENMARK | *The Copenhagen Post* – 20 October 2017 – Figures revealed in *Momentum*, the newsletter sent out by Kommunernes Landsforening, the umbrella organisation for municipalities, show that the number of Danes dying in hospital or a hospice over the last 35 years has fallen from 54 to 43%. More specifically, the figure for people dying at home, in an old peoples' home, or other place outside hospital, was 57% in 2016. Experts feel that the health system and the municipalities can do a lot more to assist people with a dignified death in familiar surroundings. <https://goo.gl/h9ypF5>

End-of-life care in New Zealand

Hospices deprived of strong painkillers due to “safety concerns”

NEW ZEALAND | Radio New Zealand (Wellington) – 20 October 2017 – Patients don't have access to stronger pain-killing drugs because they aren't fully-funded, top New Zealand hospice and palliative care (PC) doctors say. They said that was mainly due to inequalities between hospitals and hospices. Pharmac [the government agency that decides which pharmaceuticals to publicly fund in New Zealand] said many painkilling drugs were “open-listed” – meaning anyone can theoretically access them, but the man who co-wrote Pharmac's PC handbook, Rod MacLeod, said at Hibiscus Hospice in Auckland he can't get hold of a “rapid-onset, short-acting strong painkiller. If you're having any incident pain or what's called breakthrough pain or sudden acute severe pain, you want something that works within minutes, not within 15 or 20 minutes,” he said. <https://goo.gl/vPKkCH>

End-of-life care in England

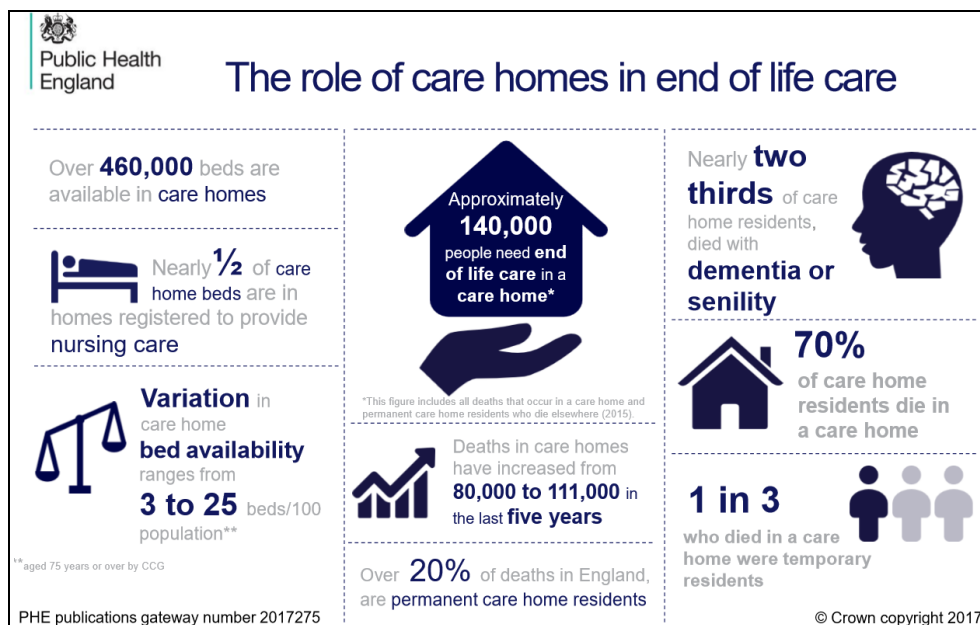
The role of care homes in end-of-life care

U.K. (England) | National End-of-Life Care Intelligence Network – 19 October 2017 – Two briefings describe the actual and potential role of care homes in provision of end-of-life care (EoLC) for people aged 75 years or over. Care homes are becoming an increasingly important place for EoLC as the population ages because the weeks, months, and sometimes years before death are marked, for many, by physical and mental decline, frailty and increasing need for support and care. It is also recognised that for many people the acute hospital setting may not be the best place to provide EoLC. In 2015, 493,498 people died in England of whom 111,738 (23%) died in a care home. The number

of deaths in care homes has increased from 87,751 (20%) in 2011. Care homes are a major provider of EoLC. 105,099 permanent care home residents (all ages) died in 2015, 71% (74,634) of these died in a care home and 29% (30,465) died elsewhere, predominantly in hospital. <https://goo.gl/QPP3HE>

Specialist Publications

'State of health and care in England' (p.7), in *British Medical Journal*.



Cont.

Noted in Media Watch 16 October 2017 (#534, p.16):

- **PALLIATIVE MEDICINE** | Online – 10 October 2017 – ‘**What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death.**’ Projections show that there will be substantial increases in deaths at home and in care homes over the next 25 years, if current trends continue, putting significant pressure on community services. If the reduction of deaths in hospital is to be sustained, there is an urgent need to expand the number of care home places and invest in community services and social care. **Full text:** <https://goo.gl/nhXAVS>

Noted in Media Watch 14 August 2017 (#525, p.4):

- U.K. (England) | Public Health England – 8 August 2017 – ‘**Results of a national survey of support to adult care homes in England: A specialist palliative care provider perspective.**’ Although there were some limitations to the quantitative data, providers written accounts helped to identify weaknesses in data capture relating to care home residents. The richness of their free text contributions have in particular, enhanced our understanding of the challenges and potential enablers to the delivery of support from an specialist palliative care (SPC) provider perspective. <https://goo.gl/eiCwQA>

End-of-life care in Australia

Study shows costly futile treatments for the dying rob them of dignified end

AUSTRALIA (Queensland) | *The Courier-Mail* (Brisbane) – 15 October 2017 – Unnecessary medical procedures performed on dying patients are costing Australian taxpayers as much as \$153 million a year, Queensland research has found. And these “futile” treatments could be unwittingly robbing patients of a dignified, peaceful death, experts have warned. A joint Queensland University of Technology (QUT) and University of Queensland study¹ ... has shown non-beneficial end-of-life (EoL) treatments were estimated to cost the health system 41,222 bed days or \$153 million a year. Lead researcher and QUT health economist Hannah Carter said unless something was done this figure would only increase, with the number of deaths in Australia tipped to double over the next 25 years. “I guess to put it in layman’s terms, we are talking about treatment that can quite often be invasive or burdensome for the patient who receives it, but it makes little difference to their survival and it can actually have the effect of reducing quality

of life in a patient’s last few days or week,” she said. The study ... found on average more than 12% of EoL patients received so-called “futile” treatment while in hospital that lasted for an average of 15 days, including five days in intensive care. <https://goo.gl/YSu572>

More than AU\$60 million boost for projects to improve quality and access to palliative care in Australia

AUSTRALIA | *OpenGov Asia* – 16 October 2017 – The funding announced includes AU\$45.4 million through the National Palliative Care Projects grants initiative for 12 projects that will help people on their final journey and their families, with end-of-life care. The Government will also provide AU\$15 million over three years from 2017-2018 for the National Specialist Palliative Care & Advance Care Planning Advisory Services project. <https://goo.gl/ktQcey>

1. ‘Incidence, duration and cost of futile treatment in end-of-life hospital admissions to three Australian public-sector tertiary hospitals: A retrospective multicentre cohort study,’ *BMJ Open*, published online 16 October 2017. **Full text:** <https://goo.gl/stU8vf>

N.B. Additional articles on medical futility are noted in the 26 June 2017 issue of Media Watch (#518, p.8).

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Specialist Publications

Palliative nephrology: Time for new insights

AMERICAN JOURNAL OF KIDNEY DISEASES, 2017;70(5):593-595. Palliative nephrology initiatives in both the U.S. and the U.K. have influenced how care is delivered toward the end of life, although practice across countries is notably different. In the U.S., pioneering work in the 1990s led to developments in palliative care for dialysis patients and a focus of research, policy, and practice on dialysis therapy withdrawal. Conversely, in the U.K., the emphasis has been on developing conservative (nondialytic) management programs. In palliative nephrology, a creative dynamic among practice, research, and policy has emerged, although there remain important differences in these areas between the U.S. and the U.K. **Full text:** <https://goo.gl/KfFHqk>

Noted in Media Watch 17 April 2017 (#508, p.8):

- *CURRENT OPINION IN NEPHROLOGY & HYPERTENSION* | Online – 7 April 2017 – ‘**Palliative and end-of-life care in nephrology: Moving from observations to interventions.**’ In comparison with patients who have other serious illnesses, patients with advanced kidney disease have a higher rate of intensive care utilization at the end of life and receive palliative care (PC) less frequently. Consensus and clinical practice guidelines have therefore recommended the incorporation of PC earlier in the disease trajectory. **Abstract:** <https://goo.gl/QGfH50>

N.B. Additional articles on palliative and end-of-life care in nephrology are noted in the 24 April 2017 issue of Media Watch (#509, p.15).

Care Quality Commission

State of health and care in England

BRITISH MEDICAL JOURNAL | Online – 17 October 2017 – The annual assessment of health and social care by the Care Quality Commission (CQC) provides a veritable treasure trove of information about the state of services in England.¹ Based on inspections of 21,256 adult social care services, 152 National Health Service (NHS) acute trusts, 197 independent acute hospitals, 18 NHS community health trusts, 54 NHS mental health trusts, 226 independent mental health locations, 10 NHS ambulance trusts, and 7,028 primary care services over three years, the assessment offers grounds for concern and reassurance in equal measure. The CQC’s headline finding is that most services are good and many providers have improved the quality and safety of care since inspections. Behind this

headline lies a much more nuanced assessment, with variations between and within services and evidence of growing pressures on staff and deterioration of quality in some services. **Introduction:** <https://goo.gl/L73Edd>

Extract from Care Quality Commission report

Hospices were generally rated as good (70%) with a quarter rated as outstanding – this was higher than for any other secondary care service. Hospices also performed very well for safety in comparison with the majority of other types of services – 88% were rated as good and 1% as outstanding. And hospices are very caring and compassionate with a third rated as outstanding for caring.

1. ‘The state of health care and adult social care in England 2016-2017,’ Care Quality Commission, October 2017. **Download/view report at:** <https://goo.gl/hT5BQe>

Noted in Media Watch 16 October 2017 (#534, p.5):

- U.K. (England) | Care Quality Commission – 10 October 2017 – ‘**The state of hospice services in England, 2014-2017.**’ The regulator’s latest ratings data shows over 90% (34 out of 37 hospices) inspected so far have been judged to be providing outstanding or good care. These ratings mark one year on since the Commission introduced its more rigorous and expert-led approach that assesses hospices across England on whether they are safe, caring, effective, responsive to people’s needs and well-led. **Download/view report at:** <https://goo.gl/2Zu6oq>

Encouraging an assets rather than a deficits approach to the last phase of life

BRITISH MEDICAL JOURNAL | Online – 14 October 2017 – To boldly go... Death is the final frontier that we will all face. But sudden death is dying out, and dying nowadays takes longer, with a last phase of life giving us months or years to consider our fate. How we respond in that situation will have immense consequences on how we will die. If we consider that talking about dying is in itself negative or harmful to hope, we lose a great opportunity to get actively involved in planning what we want, and to bringing our own personal beliefs and assets, and our friends' resources to the table. If we hope against hope for a cure, we may receive treatment of doubtful or even no benefit for us. We will also be less likely to receive comprehensive care that brings comfort and dignity, and miss the opportunity to influence and personalise our own dying. We will all die one day, so let's try to make sense of it. The ability to make sense of stresses helps people cope and make life more manageable. This capability is applicable to the last phase of life, just as it is throughout life. **Full text:** <https://goo.gl/zfudSj>

Till death do us part: The evolution of end-of-life and death attitudes

CANADIAN JOURNAL OF CRITICAL CARE NURSING, 2017;28(3):34-40. Death within the realm of nature is simply the cessation of life. In humanity, the simplicity of this concept over the last century has evolved dramatically, as medical progression, technological advancement and research have instrumentally changed the face of death. This new death culture has never been more present than within the critical care environment, its sole purpose fashioned precisely from the use of modern medicine and technology to aggressively treat, prolong and save human life. At present, people are living longer, but quality of life is heavily impacted by co-morbidities, disease and both physical and mental decline. As such, the critically ill patient today is more complex and fragile than ever before and the use of available technology often leads to a poor quality of life at end of life (EoL) for patients on the trajectory toward death. Alongside the aggressive medical determination to prolong life, time has also seen the development of palliative care and now medical assistance in dying from a desire and demand for a better death. Examining trends of past and present influences and compelling change factors, as they relate to death, provides a compass for predicting and providing insight into future EoL experiences and death attitudes. For critically ill patients, this will be a fundamentally essential need. **Abstract:** <https://goo.gl/BTpSG4>

Related

- *THE JOURNALS OF GERONTOLOGY: SERIES A* | Online – 12 October 2017 – 'What is the end-of-life period? Trajectories and characterization based on primary caregiver reports.' As the population lives longer, end of life (EoL) is emerging as a distinct life phase, about which there is still limited understanding. Characterizing this important period is vital for clarifying issues regarding trajectory and decline at EoL and for health service planning on an institutional, communal, and societal level. The authors aim to characterize the EoL period, examining the duration and number of EoL stages, as well as the functional, attitudinal and emotional trajectories. **Abstract:** <https://goo.gl/iiCFRN>

End-of-life care in Taiwan

From vulnerability to passion in the end-of-life care: The lived experience of nurses

EUROPEAN JOURNAL OF ONCOLOGY NURSING | Online – 13 October 2017 – End-of-life care (EoLC) is considered to be inherently difficult and vulnerable for patients and nurses. It also seems hard to develop passion for care during these problematic times. This study elucidates how end-of-life nurses interpret their care experience and how they transform their experience and mindset. The results showed that nurses who provide EoLC actually experience suffering by witnessing patients' suffering. However, the suffering authentically drives the nurses to encounter their own inner selves, to induce the shift of mindset, and then allow them to continuously provide and maintain the passion in EoLC. This study provides a new viewpoint for understanding of end-of-life nurses' experiences, indicating that this line of work may be recognized as a privilege. **Abstract:** <https://goo.gl/vmpqNN>

Cont.

Noted in Media Watch 3 July 2017 (#519, p.4):

- TAIWAN | *The Taipei Times* – 29 June 2017 – ‘**Doctors still adjusting to concept of palliative care.**’ The promotion of palliative care (PC) has met opposition from doctors who say it contravenes their duty to save lives, a physician from Taipei City Hospital said. Many doctors found it difficult to let go of patients when the hospital first began promoting PC, despite the doctors being fully trained for the procedure, Taipei City Hospital director Huang Sheng-chien said. <https://goo.gl/sPoEFk>

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

Discussing advance care planning: Insights from older people living in nursing homes and from family members

INTERNATIONAL PSYCHOGERIATRICALS | Online – 9 October 2017 – Evidence concerning when and in which manner older people living in nursing homes (NH) would prefer to discuss advance care planning (ACP) is still scarce. This study explored the attitudes of NH residents and family members toward ACP and their opinions as to the right time to broach the subject, the manner in which it should be approached, and the content of ACP. Three main themes were identified: 1) Life in the NH, including thoughts about life in a nursing home, residents’ concerns, wishes and fears, and communication barriers; 2) Future plans and attitudes toward ACP, including attitudes toward planning for the future and plans already made, and attitudes toward and barriers against ACP; and, 3) Contents and manner of ACP, including contents of ACP discussions, the right moment to introduce ACP, with whom it is better to discuss ACP, and attitudes toward advance directives. ACP was a welcome intervention for the majority of participants[in this study], but an individualized assessment of the person’s readiness to be involved in ACP is needed. Participants in suggested ACP should include palliative care and

practical issues, and that in the NH setting all staff and family members may have a valuable role in ACP. **Abstract:** <https://goo.gl/Xg597i>

Implementation of advance care planning in Israel: A convergence of top-down and bottom-up processes

THE GERONTOLOGIST | Online – 13 October 2017 – The authors present an example of the processes of change regarding advance care planning (ACP) and preparing advance directives (ADs) that have begun to take place in Israel in recent years. They argue that these processes derive from the synergy between legislation on the one hand, and initiatives and action by health organizations on the other. In other words, top-down action such as legislation and directives issued by the Ministry of Health in the past decade, alongside bottom-up action in the health plans and other organizations, have led to change that could not have happened without either side. In the first part of the article, the authors present Israel’s Dying Patient Act and its ensuing amendments and in the second part, they present examples of activities in the health services. **Abstract:** <https://goo.gl/7CDUPp>

Noted in Media Watch 15 August 2016 (#475, p.10):

- *PATIENT EDUCATION & COUNSELLING* | Online – 10 August 2016 – ‘**Advance care planning for nursing home residents with dementia: Influence of ‘we DECide’ on policy and practice.**’ Advance care planning (ACP) policy was significantly more compliant with best practice after ‘we DECide’; policy in the control group was not. ACP was not discussed more frequently, nor were residents and families involved to a higher degree in conversations after ‘we DECide.’ Barriers to realizing ACP included staff’s limited responsibilities; facilitators included support by management staff, and involvement of the whole organization. **Abstract:** <http://goo.gl/mteikl>

Noted in Media Watch 28 September 2015 (#429, p.13):

- *PALLIATIVE MEDICINE* | Online – 22 September 2015 – ‘**They know! Do they? A qualitative study of residents and relatives views on advance care planning, end-of-life care, and decision-making in nursing homes.**’ The main findings were the differing views about decision-making and advance care planning (ACP) of residents and relatives. Residents trust relatives and staff to make important decisions for them. The relatives are, in contrast, insecure about the residents’ wishes and experience decision-making as a burden. The majority of the residents had not participated in ACP; none stated challenges connected to end-of-life care. **Abstract:** <https://goo.gl/yMUjtZ>

Forgiveness facilitation in palliative care: A scoping review protocol

JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS, 2017;15(10):2469-2479. Research on forgiveness is dispersed in the literature, and has been conducted in different clinical settings but mainly in palliative care (PC) contexts. Some outcomes have been related to forgiveness, such as better life satisfaction, increased blood pressure, positive mental health, physical and emotional well-being, and lower levels of depression and anxiety. Also, forgiving (others or self) is important in reducing the sense of guilt, which has been suggested as an indicator of spiritual distress in patients with acute renal failure or cancer patients undergoing chemotherapy. Forgiving is also associated with a greater sense of hope and optimism in the future, and the willingness to forgive relieves negative self-esteem. Forgiveness may be associated with better spiritual health, as the experience of forgiving facilitates the act of letting go and brings about inner peace, even for those who are not religious. Regardless of the knowledge about forgiveness in health, it is not clear in the literature which healthcare team members usually provide forgiveness facilitation and neither are the outcomes related to that intervention in the context of PC. **Full text:** <https://goo.gl/6rD6z9>

Noted in Media Watch 6 July 2015 (#417, p.9):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 2 July 2015 – ‘**Provider difficulties with spiritual and forgiveness communication at the end of life.**’ The majority of study participants were involved in spiritual and forgiveness communication. Difficult communication included talking with family after death and facilitating forgiveness between patients and families. These findings support the importance of spiritual communication in clinical practice, and the need for clinician training in communicating about spirituality and forgiveness. **Abstract:** <https://goo.gl/eBNaUB>

Noted in Media Watch 6 August 2012 (#265, p.6):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 July 2012 – ‘**Forgiveness, depressive symptoms, and communication at the end of life: A study with family members of hospice patients.**’ Forgiveness has begun to receive empirical attention in end-of-life contexts, but primarily among patients. Although not as commonly endorsed as expressions of love and gratitude, forgiveness-related communications are seen as extremely important by many family members of hospice patients. **Abstract:** <https://goo.gl/Dn1Yhp>

End-of-life care in Sweden

Symptom relief and palliative care during the last week of life among patients with heart failure: A national register study

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 October 2017 – Only 4.2% of [3,981] patients with heart failure received specialized palliative care. In their last week of life, symptom prevalence was high, validated scales were seldom used, and symptoms were unsatisfactorily relieved. Around one-fifth (17%) of the patients in the study died alone. Less than half of family members had been offered bereavement support (45%). Moreover, one-third (28%) of the patients and more than half (61%) of the family members were reported to have had end-of-life discussions with a physician during the illness trajectory. **Abstract:** <https://goo.gl/QYiQFh>

N.B. Additional articles on end-of-life care for people living with heart failure are noted in the 16 October 2017 issue of Media Watch (#534, pp.10-11).

Related

- *PLOS ONE* | Online – 19 October 2017 – ‘**Improved data validity in the Swedish Register of Palliative Care.**’ The national quality register collects data about end-of-life care from healthcare providers that care for dying patients. Data are used for quality control and research and are mainly collected with an end-of-life questionnaire (ELQ), which is completed by healthcare staff after the death of a patient. A previous validity assessment of the ELQ showed insufficient validity in some items including symptom relief. **Full text:** <https://goo.gl/28CiGf>

A milestone for palliative care and pain relief

THE LANCET | Online – 12 October 2017 – Why have palliative care (PC) and pain relief been so ignored in global health? Two reasons might be considered. First, PC and pain relief are often seen as luxuries for health-care systems. Even high-income countries with advanced health services struggle to provide access to comprehensive PC programmes. It would be unreasonable, some may argue, to include PC and pain relief as core services for universal health coverage (UHC). Second, in those high-income countries where PC and pain relief are available, there is often vigorous and passionate disagreement about the role of PC services in end-of-life settings. If the professional, public, and political communities cannot agree on the place of PC in society, introducing this element into discussions of what should be included within UHC is unlikely to be helpful or productive. *This Lancet Commission* shows that these arguments and assumptions are entirely fallacious.¹ **Full text:** <https://goo.gl/GhSWXs>

1. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, published online 12 October 2017 [Noted in Media Watch 16 October 2017 (#534, p.14)] **Full text:** <https://goo.gl/i7r9M1>

Palliative care in interstitial lung disease: Living well

THE LANCET: RESPIRATORY DISEASE | Online – 12 October 2017 – Progressive fibrotic interstitial lung diseases (ILDs) are characterised by major reductions in quality of life (QoL) and survival, and have similarities to certain malignancies. However, palliative care (PC) expertise is conspicuously inaccessible to many patients with ILD. Unmet patient and caregiver needs include effective pharmacological and psychosocial interventions to improve QoL throughout the disease course, sensitive advanced care planning, and timely patient-centred end-of-life care (EoLC). The incorrect perception that PC is synonymous with EoLC, with no role earlier in the course of ILD, has created a culture of neglect. Interventions that aim to improve life expectancy are often prioritised without rigorous assessment of the individual's health and psychosocial needs, thereby inadvertently reducing QoL. As in malignant disorders, radical interventions to slow disease progression and palliative measures to improve quality of life should both be prioritised. Efficient patient-centred models of PC must be validated, taking into account religious and cultural differences, as well as variability of resources. Effective implementation of PC for ILD will require multidisciplinary participation from clinicians, specialist nurses, psycholo-

gists, social workers, and, in some countries, non-governmental faith and community-based organisations with access to PC expertise. **Full text:** <https://goo.gl/yBaK5G>

Universal coverage for palliative care in respiratory disease and critical care

THE LANCET: RESPIRATORY DISEASE | Online – 12 October 2017 – Too many people live and die with serious health-related suffering. The Lancet Commission on palliative care and pain relief is a powerful reminder of the global need to address this issue. The authors estimate that worldwide, 25.5 million people die with suffering and more than 6 billion days are lived with suffering each year. Lung disease is the third leading cause of serious health-related suffering, accounting for 2.8 million deaths and more than 750 million days of suffering in low-income and middle-income countries.¹ **Full text:** <https://goo.gl/nwgsKD>

1. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, published online 12 October 2017 [Noted in Media Watch 16 October 2017 (#534, p.14)] **Full text:** <https://goo.gl/i7r9M1>

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Noted in Media Watch 25 September 2017 (#531, p.12):

- *THE HIPPOCRATIC POST* | Online – 20 September 2017 – ‘**A crisis in care for people with lung disease.**’ People who are dying from interstitial lung disease (ILD) are wasting the precious time they have left finding their way around an ineffective and unnecessarily complicated healthcare system. That’s according to a report by the British Lung Foundation.¹ The report focuses on the most common ILD, idiopathic pulmonary fibrosis. A condition, with an average life expectancy of just three years after diagnosis, which affects around 32,000 people in the U.K. **Full text:** <https://goo.gl/5SKzZt>
1. ‘A map for better care: Making effective care pathways for people with interstitial lung disease (ILD), highlights the crises in ILD care,’ British Lung Foundation, September 2017. **Download/view report at:** <https://goo.gl/RVa8GL>

Defining unique needs for palliative and hospice care in Huntington disease

NEUROLOGY ADVISOR | Online – 19 October 2017 – The course of Huntington disease (HD) can take decades to fully evolve from the early hallmarks of chorea, mood disturbances, and mild cognitive impairment to end-stage disease in which patients often die from complications of dementia and/or significant decline in motor function. Palliative and hospice care play an important role in the long-term management of HD, including ongoing symptom relief measures, caregiver support, and end-of-life care (EoLC). Services offered by palliative care (PC) and hospice often overlap significantly, particularly in imminently terminal conditions such as cancer and heart disease, where progression is much more rapid than in HD. PC and hospice both focus on comfort measures and EoLC when the benefits of disease-modifying treatments have been exhausted. By definition, patients must be given a prognosis of 6 months’ survival or less by two physicians to receive Medicare benefits for hospice [in the U.S.]. **Full text:** <https://goo.gl/TS3UQs>

Noted in Media Watch 18 September 2017 (#530, p.17):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 September 2017 – ‘**Utilization of hospice services in a population of patients with Huntington’s disease.**’ In this retrospective cohort study of electronic medical record data from 12 not-for-profit hospices in the U.S. from 2008 to 2012, patients with HD are admitted to hospice at a younger age compared to other patients (57 versus 76 years old), but have a significant symptom burden and limited functional status. Although hospice care emphasizes the importance of helping patients to remain in their homes, only a minority of these patients were able to die at home. **Abstract:** <https://goo.gl/WwQVB2>

N.B. Additional articles on end-of-life care for patients and family living with Huntington’s disease are noted in the 19 June 2017 issue of Media Watch (#517, p.6)]

Cross-cultural differences in communication about a dying child

PEDIATRICS | Online – 19 October 2017 – There are more migrants, refugees, and immigrants adrift in the world today than at any time in the recent past. Doctors and hospitals must care for people from many different cultures, countries, and religious backgrounds. We sometimes find our own deeply held beliefs and values challenged. The authors present a case in which a Pakistani immigrant family faces a tragic medical situation and wants to deal with it in ways that might be normative in their own culture but are aberrant in ours. They asked the American doctors and 2 Pakistani health professionals to think through the issues. The authors also invited the father to talk about his own experience and preferences. They conclude that strict adherence to Western ethical norms may not always be the best choice. Instead, an approach based on cultural humility may often allow people on both sides of a cultural divide to learn from one another. **Abstract:** <https://goo.gl/i9bEA8>

Religious affiliation at time of death: Global estimates and projections

SCANDINAVIAN JOURNAL OF PUBLIC HEALTH | Online – 16 October 2017 – Religious affiliation influences societal practices regarding death and dying, including palliative care, religiously acceptable health service procedures, funeral rites and beliefs about an afterlife. The authors compiled data on demographic information and religious affiliation from more than 2,500 surveys, registers and censuses covering 198 nations/territories. They present estimates of religious affiliation at the time of death as of 2010, projections up to and including 2060, taking into account trends in mortality, religious conversion, inter-generational transmission of religion, differential fertility, and gross migration flows, by age and sex. The authors find that Christianity continues to be the most common religion at death, although its share will fall from 37% to 31% of global deaths between 2010 and 2060. The share of individuals identifying as Muslim at the time of death increases from 21% to 24%. The share of religiously unaffiliated will peak at 17% in 2035 followed by a slight decline thereafter. In specific regions, such as Europe, the unaffiliated share will continue to rise from 14% to 21% throughout the period. Religious affiliation at the time of death is changing globally, with distinct regional patterns. This could affect spatial variation in healthcare and social customs relating to death and dying. **Abstract:** <https://goo.gl/i8zpxg>

Noted in Media Watch 23 January 2017 (#496, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 January 2017 – ‘**A systematic review of religious beliefs about major end-of-life issues in the five major world religions.**’ The authors’ search strategy generated 968 references, 40 of which were included for this review. Whenever possible, they organized the results into five categories that would be clinically meaningful for palliative care practices at the end-of-life (EoL): 1) Advanced directives; 2) Euthanasia and physician-assisted suicide; 3) Physical requirements (artificial nutrition, hydration, and pain management); 4) Autopsy practices; and, 5) Other EoL religious considerations. **Abstract:** <https://goo.gl/0Lh72z>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ANNALS OF EMERGENCY MEDICINE* | Online – 13 October 2017 – ‘**No easy way out: A case of physician-assisted dying in the emergency department.**’ Currently, 1 out of 6 Americans lives within a jurisdiction in which physician-assisted dying (PAD) is legally authorized. In most cases, patients ingest lethal PAD medications at home without involvement of emergency medical services (EMS) or the emergency department (ED). However, occasionally the dying process is interrupted as a result of incomplete ingestion or vomiting of medications, confusion about timing of dying trajectory, familial emotional distress, and other variables. A case is presented here of a patient who arrived by ambulance to an urban ED after ingesting PAD medication. Stepwise analysis of communication and actions between providers (paramedics, emergency physician, and admitting physician), risk management, and family are described chronologically. This case highlights the significant distress experienced by each party, as well as key challenges and learning points. Guidance is provided to emergency providers about expectations and communication. In states with limited PAD experience, many EMS agencies, EDs, and hospitals require comprehensive protocols to handle the complex ethical and psychosocial issues surrounding PAD in the ED. <https://goo.gl/V2tJA6>
- *BMC MEDICINE* | Online – 20 October 2017 – ‘**Voluntary stopping of eating and drinking: Is medical support ethically justified?**’ Physician-assisted dying has been the subject of extensive discussion and legislative activity both in Europe and North America. In this context, dying by voluntary stopping of eating and drinking (VSED) is often proposed, and practiced, as an alternative method of self-determined dying, with medical support for VSED being regarded as ethically and legally justified. In the opinion of the authors, this view is flawed. First, they argue that VSED falls within the concept of suicide, albeit with certain unique features (non-invasiveness, initial reversibility, resemblance to the natural dying process). Second, the authors demonstrate, on the basis of paradigmatic clinical cases, that medically supported VSED is, at least in some instances, tantamount to assisted suicide. This is especially the case if a patient’s choice of VSED depends on the physician’s assurance to provide medical support. **Full text:** <https://goo.gl/DHbpGk>

Cont.

Commentary

The authors compare and contrast two leading end-of-life exit options, namely voluntarily stopping eating and drinking (VSED) and medical aid in dying (MAiD). They argue that policymakers and medical societies should consider VSED and MAiD in a uniform and consistent manner given that clinician participation in both constitutes assisted suicide. This is a very controversial topic. It is questioned whether there really is disparate consideration of VSED and MAiD and whether it is justified, bearing in mind that VSED is not assisted suicide. **Full text:** <https://goo.gl/onwqJR>

N.B. Additional articles on voluntarily stopping eating and drinking are noted in the 17 October 2016 issue of Media Watch (#483, p.14).

Worth Repeating

Do models of care designed for terminally ill “home alone” people improve their end-of-life experience? A patient perspective

HEALTH SOCIAL CARE IN THE COMMUNITY | Online – 14 July 2012 – This article describes the experiences of terminally ill “home alone” people using one of two models of care aimed at maintaining participants’ need for independent living, focusing on the effect of these two models of care on their physical, social and emotional needs. The care-aide model of care resulted in benefits such as easing the burden of everyday living; supporting well-being; enhancing quality of life and preserving a sense of dignity; and, reducing loneliness and isolation. The personal alarm model of care imparted a sense of security; provided peace of mind; and, helped to deal with feelings of isolation. Participants in both groups felt that they could remain at home longer. By providing a safer, more secure environment through the use of a personal alarm or additional care-aide hours, patients were able to continue their activities of daily living, could build a sense of “normality” into their lives, and they could live independently through support and dignity. [Noted in Media Watch 16 July 2012 (#262, p.10)] **Abstract:** <https://goo.gl/qJCMwm>

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

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

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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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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/3oecYD>

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

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

PALLIMED: <http://goo.gl/7mrqMQ>

[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/XO4mD>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLqxy2>
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>
[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

ONTARIO | Mississauga Halton Palliative Care Network: <https://goo.gl/ds5wYC>
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Europe



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

HUNGARY | Magyar Hospice Alapítvány: <http://goo.gl/5d1I9K>

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

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