

## 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.

18 January 2016 Edition | Issue #445



Compilation of Media Watch 2008-2016 ©

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Effecting change in the illness experience: Scroll down to [Specialist Publications](#) and 'A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work?' (p.12), in *Patient Education & Counseling*.

## Canada

### Canada needs to guarantee access to palliative care, report says

CTV NEWS | Online – 12 January 2016 – Federal and provincial governments need to guarantee access to palliative care (PC) in legislation, the Canadian Cancer Society said ... as it released a report on the state of [end-of-life] care across the country.<sup>1</sup> In its findings, the society said critically ill patients are falling through the cracks of the health care system and improvements are needed to address the patchwork of service that exists. In the absence of national standards, individual jurisdictions are left to develop their own policies, programs and guidelines that result in inconsistent and inadequate PC, the report said. Canada must reform its approach to PC, according to the society's public issues director Gabriel Miller. "We haven't, as a country, guaranteed this as part of what Canadians have a right to expect from their health care system," he said. "We haven't developed the

standards or the data collection we need to make sure it is being provided properly, and we haven't made the targeted investments to make sure that people can get the right kind of care where they need it. "It is absolutely now that governments have to take action to fix that." Fixing PC must be at the top of the to-do list for the federal and provincial governments as work begins on a new health accord, Miller noted. <http://goo.gl/rZbmN8>

#### Extract from Canadian Cancer Society report

Without clear national standards and accountabilities, individual jurisdictions are left to develop their own policies, programs and guidelines, resulting in inconsistent or inadequate access across the country.

1. 'Right to Care: Palliative care for all Canadians,' Canadian Cancer Society, December 2015. <http://goo.gl/f3iFEB>

Cont. next page

### 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.14.

## Related

- SASKATCHEWAN | *The Saskatoon Star-Phoenix* (OpEd) – 11 January 2016 – **‘Improve palliative, hospice care in Saskatchewan.’** Why are there only three, or perhaps four, if I include myself, full-time qualified palliative care (PC) physicians in this province? Why are there only nine acute PC beds and 10 hospice beds in Regina, and just 14 PC beds and no hospice beds in Saskatoon? There is the occasional dedicated PC bed in other hospitals in Saskatchewan, but the sad fact is that the majority of the elderly, chronically ill die in nursing homes with less than satisfactory end-of-life care. When will the bureaucrats in the health-care regions and the politicians in government accept the fact that death is inevitable and PC is as vital as any other branch of medicine? <http://goo.gl/8xiQZh>

### Access to palliative care in Canada

In 2005, Senator Sharon Carstairs, Canada’s first and only Minister with Special Responsibility for Palliative Care (2001-2003), had estimated no more than 15% of Canadians had access to palliative care (PC). In 2007, in the only statistically significant study published to that date, the Canadian Institute for Health Information estimated people living with a terminal illness in British Columbia, Alberta, Saskatchewan and Manitoba were referred to PC only 35-37% of the time; a low of 16% if the terminal illness was *not* cancer. A 2009 Université Laval press release estimated the number at 10%. In recent years, the Canadian Hospice Palliative Care Association estimates have varied from a low of 15% to a high of 30%. The Quality of End-of-Life Care Coalition of Canada has been even less specific – “only a small portion of those who die receive PC.”

Access to pediatric PC? A 2007 study indicated that “only a small percentage (5-12%) of children who die in Canada receive specialized end-of-life care (EOLC).” **BRA**

**N.B.** For a listing of nine key studies on EOLC in Canada, published between 1995-2014, see Media Watch, 22 December 2014, #389 (p.4).

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | *The Chronicle Herald* (Halifax) – 16 January 2016 – **“‘Enormous consequence’: Nova Scotia doctors issue draft standard on assisted death.’** The College of Physicians & Surgeons of Nova Scotia released the draft standard of practice for physician-assisted death. The document is in response to the [Supreme] court’s unanimous ruling ... striking down the ban on physician-assisted death and giving eligible patients the right to receive help from a willing physician. Since then, the college, in partnership with the Health & Wellness Department, Doctors Nova Scotia, the provincial health authority and Dalhousie University’s health law institute, has worked on the draft document. <http://goo.gl/JbvKUV>
- CBC NEWS | Online – 15 January 2016 – **‘Supreme Court gives federal government 4-month extension to pass assisted dying law.’** In a 5-4 ruling the Supreme Court of Canada has granted the federal government a four-month extension to pass assisted dying legislation, rather than the six months the government had asked for. The court also ruled that Quebec’s assisted dying law, which came into effect in December, can remain in effect. <http://goo.gl/AytXrd>
- *THE TORONTO STAR* | Online – 11 January 2016 – **‘Ottawa surprises top court judges by allowing assisted suicide to proceed in Quebec.’** Ontario is scrambling to catch up to Quebec where doctors could soon legally aid terminally ill adult patients to kill themselves after a stunning offer by federal lawyers to recognize – for now – the legality of Quebec’s right-to-die regime [i.e., Bill 52, An Act respecting end-of-life care]. Federal lawyer Robert Frater made the surprise concession at a Supreme Court of Canada hearing where he sought a six-month extension for federal politicians to rewrite assisted suicide laws to provide more “clarity” to protect vulnerable people. Frater said only Quebec has come up with a “comprehensive scheme” to address concerns of physicians and patients after the high court ruled last year that people suffering a “grievous and irremediable medical condition” must be allowed to seek a doctor’s help to end their lives. <http://goo.gl/6ZDDvK>

## U.S.A.

### Doctors need to learn about dying, too

*THE WASHINGTON POST* | Online – 15 January 2016 – Starting this year, Medicare will, for the first time ever, reimburse physicians for having end-of-life discussions with terminally ill patients. In the ideal scenarios, doctors ask patients to identify how and where they want to spend those final days, and then recommend the best options. Question is, will physicians, as a result, be motivated to initiate more of these crucial conversations? Will patients? And will this long-overdue reform ultimately improve, both clinically and economically, how well the U.S. health care system delivers end-of-life care? Nobody knows for sure. But this much is certain: Many physicians have received no training along these lines. Few are educated in how to carry on this kind of talk with patients in the first place, much less in shepherding patients compassionately toward death. In 1999, only 26% of resi-

duency programs in the U.S. offered a course on care at the end of life as part of the curriculum, the *Journal of the American Medical Association* reported. Indeed, of 122 medical schools researchers surveyed more recently, only eight had mandatory coursework in end-of-life care. <https://goo.gl/M3Rlnr>

#### Specialist Publications

'Training methods and objectives of current hospice volunteer training programs' (p.6), in *American Journal of Hospice & Palliative Medicine*.

'End-of-life care in the Hispanic community' (p.10), in *Journal of Hospice & Palliative Nursing*.

#### Selected articles on palliative care education in the U.S.

- *JOURNAL OF CANCER EDUCATION* | Online – 9 December 2014 – '**Inadequacy of palliative training in the medical school curriculum.**' The literature expresses concerns about the varied and non-uniform approach to palliative care training across medical schools. The authors recommend the development of more assessment tools in order to aid in the standardization of curriculum involving end-of-life care. [Noted in Media Watch, 15 December 2014, #388 (p.13)] <http://goo.gl/7JLhxb>
- *MEDICAL EDUCATION*, 2014;48(1):59-66. '**Palliative care education in U.S. medical schools.**' A review of U.S. medical school surveys reveals varied and uneven approaches. Palliative care competencies are too complex and universally important to be relegated to a minimum of classroom time, random clinical exposures, and the hidden curriculum. [Noted in Media Watch, 23 December 2013, #337 (p.15)] <http://goo.gl/H7q4tf>

#### Selected articles on the palliative care workforce in the U.S.

- *ANNALS OF INTERNAL MEDICINE* | Online – 20 October 2015 – '**Evolving the palliative care workforce to provide responsive, serious illness.**' The U.S. is currently in the midst of a national crisis in providing accessible and responsive palliative care due to a shortage of professionals trained to provide this care. [Noted in Media Watch, 26 October 2015, #433 (p.8)] <http://goo.gl/6LGk3X>
- *HEALTH LEADERS* | Online – 13 July 2012 – '**Palliative care challenged by physician shortage.**' There is about one cardiologist in the U.S. for every 71 people experiencing a heart attack; one oncologist for every 141 newly diagnosed cancer patients; and, only one palliative care physician for every 1,200 people living with a life-threatening illness. [Noted in Media Watch, 16 July 2012, #262 (p.10)] <http://goo.gl/0IKQHB>

#### Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: <http://goo.gl/frPgZ5>

## International

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

#### **Patients at end of life face a postcode lottery doctors warn**

U.K. | *The Daily Mirror* – 14 January 2016 – Patients face a postcode lottery on end-of-life care (EOLC), doctors warn. The British Medical Association (BMA) said it has to be made a top priority after a review found services varied according to geography and the illnesses people were suffering.<sup>1</sup> Support for people who are in the last months or years of their life should help them to live as well as possible until they die, and to die with dignity. But a review of services by the BMA, which represents 150,000 doctors, and social research agency TNS BRMB, found the current provision “does not match” the public’s expectations. The research found that while there were “pockets of excellence” in EOLC around the U.K., there is still a variation in the level of care between areas and between people

dying of different conditions. Dr Ian Wilson, BMA representative body chair, said: “The U.K. has led the world in developing comprehensive and holistic care for people whose lives are coming to an end. Yet this new research provides further evidence that the provision of EOLC remains variable, dependent on a patient’s geographical location, their condition, and their knowledge of local services.” <http://goo.gl/Sdc8rH>

#### Specialist Publications

‘GP workforce crisis set to undermine palliative care...’ (p.9), in *GP*.

1. ‘End-of-life care and physician-assisted dying,’ British Medical Association, January 2016. <http://goo.gl/lR5KmY>

Noted in Media Watch, 24 June 2013, #311 (p.6):

- U.K. | *The Daily Telegraph* – 19 June 2013 – ‘**Call to stop “lottery” of end-of-life care.**’ Terminally ill patients are suffering wildly varying standards of end-of-life care depending on their disease, postcode and ethnicity, a new report has found.<sup>1</sup> <http://goo.gl/Ttt2WJ>
  1. ‘People’s final journey must be one of their choosing ... Ways and Means,’ Demos, U.K., June 2013. <http://goo.gl/DroC3v>

Noted in Media Watch, 3 December 2012, #282 (p.6):

- U.K. | *The Daily Telegraph* – 28 November 2012 – ‘**Terminally ill face postcode lottery in end-of-life care.**’ Terminally ill people in London can expect a worse death than almost anywhere in the country, a study by the Office for National Statistics suggests. Analysis of a data from almost 50,000 bereaved people found wide variations in the standards of dignity, respect and basic care provided to their loved ones in different areas. <http://goo.gl/ZvESkL>

### Elder care in Scotland

#### **Hundreds die waiting for social care packages**

U.K. (Scotland) | BBC News – 13 January 2016 – More than 270 Scots died last year waiting for a social care package, figures compiled by a motor neurone disease patient and campaigner show. The former Labour party adviser Gordon Aikman sent Freedom of Information requests to Scotland’s 32 councils. Twenty six replied, revealing that at least 276 people died last year while waiting for their care to be arranged. The Scottish government said it would “continue to work hard with councils to improve provision.” Scottish Labour described the findings as “shocking.” The figures revealed that at the start of November, at least seven people had been waiting more than six months and one had been waiting nearly two years for a care package. <http://goo.gl/idhMBS>

## The best place to die in India

INDIA | The Pulitzer Center on Crisis Reporting (Washington DC) – 12 January 2016 – In India, as in much of the world, the death of a terminally-ill or elderly person is often approached as a medical failure, not a normal and inevitable course of life. And global health systems continue to promote costly treatments for often just a few extra days of low-quality life. But medical professionals and citizens in Kerala, at the southernmost tip of India, decided to put quality – not quantity – of life at the center of their health policy. For the past 20 years they have built this philosophy into an extensive palliative care (PC) program that ensures chronically ill and dying patients a more peaceful and painless end. Through state policy reform, and a deeper understanding of pain management and coun-

seling throughout the health system, Kerala is now home to the overwhelming majority of India's PC centers, has expanded access to painkillers, and trained an army of volunteers to support thousands of patients at their homes. The community-based model has been praised widely and is slowly spreading across India, where access to PC remains abysmally low at under 2% nationally. <http://goo.gl/5c3uuP>

### Specialist Publications

'Experience in strategic networking to promote palliative care in a clinical academic setting in India' (p.9), in the *Indian Journal of Palliative Care*.

Noted in Media Watch, 21 January 2013, #289 (p.4):

- INDIA | *The Times of India* – 17 January 2013 – '**Governments palliative care scheme proves a hit in Mavoor.**' A study to find the health status of patients receiving palliative care through the government home-based scheme revealed that the service has succeeded in addressing the medical, psycho-social, and supportive needs of the patients.<sup>1</sup> <http://goo.gl/cGTJzY>

1. 'Assessment of status of patients receiving palliative home care and services provided in a rural area – Kerala, India,' *Indian Journal of Palliative Care*, 2012;18(3):213-218. <http://goo.gl/cx9iq9>

**N.B.** India was ranked 67th of 80 countries surveyed in '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5> Selected articles on palliative care in India noted in past issues of Media Watch are listed in the issue of the weekly report of 28 December 2015, #442 (pp.4-5).

## End-of-life care in South Korea

### "Death with dignity" approved in parliament

SOUTH KOREA | *The Korea Times* (Seoul) – 10 January 2016 – How much pain would you endure in order to stay alive if you had an incurable illness and no prospect of leaving hospital? With the National Assembly passing the "well-dying" bill, from 2018 patients with no hope of recovery will be able to end their lives by refusing life-sustaining treatment. If a patient in possession of his or her mental faculties wishes to die like this, doctors can stop treatment such as chemotherapy, mechanical ventilation, blood dialysis and CPR. The law also applies to patients who have not expressed such a wish, if all members of their families agree. If a patient has no family, the hospital's bioethics committee can decide. At least two doctors must confirm that the patient's condition is incurable before stopping life-sustaining treatment. <http://goo.gl/MEM165>

Noted in Media Watch, 11 January 2016, #444 (p.6):

- SOUTH KOREA | *The Korea Herald* (Seoul) – 3 January 2016 – '**South Korea delays approval of death with dignity bill.**' Uncertainties loom over whether the nation's death with dignity bill will be passed before the current parliamentary term ends... <http://goo.gl/Vcf3zY>

## [Specialist Publications](#) (e.g., in-print and online journal articles, reports, etc.)

### **Accuracy of physician prognosis in heart failure and lung cancer: Comparison between physician estimates and model predicted survival**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 January 2016 – Physicians [i.e., survey respondents] were more accurate in survival estimates for lung cancer than heart failure. Cardiologists were more accurate in predicting survival in heart failure symptoms and reduced ejection fraction compared to generalists and oncologists, but no different at predicting heart failure symptoms and preserved ejection fraction. Cardiologists predicted longer survival in heart failure compared to others. Physicians felt more uncomfortable discussing palliative care with heart failure patients compared to lung cancer. <http://goo.gl/Fp686D>

#### **Related**

- *BMC PALLIATIVE CARE* | Online – 14 January 2016 – “**Sometimes we can’t fix things”: A qualitative study of health care professionals’ perceptions of end of life care for patients with heart failure.**’ The difficulty in recognising when heart failure patients are approaching the terminal phase of their condition remains a barrier to planning personalised end-of-life care in advance. There is also a lack of reliable clinical criteria and prognostic models to guide clinicians’ decision-making and inform a transition from active management to palliative care. <http://goo.gl/npTkpl>

#### **U.S. Survey**

### **Training methods and objectives of current hospice volunteer training programs**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 12 January 2016 – Currently, more than 5,800 hospice organizations operate in the U.S. Hospice organizations are required by the Centers for Medicare & Medicaid Services (CMS) to use volunteers for services provided to patients. Although CMS regulates hospice volunteer hours, there are currently no national requirements for ... training. Results [of this study] showed the majority of hospices were non-profit, had less than 100 currently trained volunteers, and maintained an average daily patient census of less than 50. Questions regarding training programs indicated that most use live lecture methods of approximately 19 hours or less in duration. A small number of respondents to this survey makes generalization nationwide difficult, however it is a strong starting point for the development of further surveys on hospice volunteer training and achieving a standardized set of training objectives and delivery methods. <http://goo.gl/pLX50P>

Noted in Media Watch, 27 July 2015, #420 (p.13):

- *COCHRANE DATABASE SYSTEM REVIEW* | Online – 20 July 2015 – ‘**Training and supportive programs for palliative care volunteers in community settings.**’ The objective of this review was to assess the effects of training and support strategies for palliative care (PC) volunteers on people requiring PC and their families, volunteers, and service quality. Despite an extensive search, the authors found no studies that they could include. <http://goo.gl/11s1sx>

**N.B.** Selected articles on the role of hospice volunteers in end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 16 February 2015, #397 (pp.8-9).

### **[Media Watch: Palliative Care Network-e Website](#)**

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://goo.gl/8JyLmE>

## How do nursing home doctors involve patients and next of kin in end-of-life decisions? A qualitative study from Norway

*BMC MEDICAL ETHICS* | Online – 14 January 2016 – This study reveals variation among nursing home doctors in how they involve patients and next of kin in end-of-life decisions, and many important decisions appear arbitrary and not based on systematic ethical reflections. Not uncommonly, the next of kin are given greater decision-making authority than they should have, sometimes also leading to interventions which are contrary to the patient's will and best interests. The few doctors who involve the patients in advance care planning as part of their routines described that they always had found this to be a good thing to do. The results underline a great need for education and supervision in ethics, law and communication for nursing home doctors, to improve the decision-making processes and avoid large and haphazard variations in practice. Improved routines for involvement of patient and next of kin may save time, energy and resources, prevent conflicts, and lead to decisions in line with the patient's values and preferences. It is not acceptable that coincidences decide whether patients are met with treatment nihilism or are provided treatment that the patient or the doctor feel is not for the best of the patient. <http://goo.gl/qAQpWZ>

**N.B.** Selected articles on end-of-life care in nursing homes noted in past issues of Media Watch are listed in the issues of the weekly report of 26 October 2015, #433 (p.10) and 15 December 2014, #388 (p.12).

### 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.

### Links to Sources

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

### Something Missed or Overlooked?

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

## Relationship between use of general practice and healthcare costs at the end of life: A data linkage study in New South Wales, Australia

*BMJ OPEN* | Online – 7 January 2016 – This analysis showed that greater use of GP services in the 18-7 months before death was associated with greater total healthcare costs at the 6 months before death, with this result driven by the costs for outpatient services and pharmaceuticals. There was no association between GP use in the 18-7 months before death and hospital inpatient costs in the last 6 months of life. These findings, to the best of the authors' knowledge, contrast starkly with results from the only previous study that has directly addressed this issue, in a large sample of U.S. Medicare beneficiaries, which found an inverse relationship between GP use and total costs.<sup>1</sup> A striking difference between the two studies was probably due to the different patterns of GP use: in this study, 42% of decedents had at least six GP visits or more in the 18-7 months before death, compared with only 22% of the U.S. decedents. This is, however, consistent with the overall higher number of annual GP visits per capita in Australia (6.5) vs. in the U.S. (3.9). Such a large gap in healthcare usage levels may reflect differences in the design, generosity and accessibility of the U.S. and Australian healthcare system, which may explain the discrepant results. <http://goo.gl/XcG3kb>

1. 'Can primary care visits reduce hospital utilization among Medicare beneficiaries at the end of life?' *Journal of General Internal Medicine*, 2008;23(9):1330-1335. <http://goo.gl/WCy80n>

## Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement

*CLINICAL PSYCHOLOGY REVIEW* | Online – 8 January 2016 – Caregivers of terminally ill patients may experience anticipatory grief or low levels of preparedness for the patient's impending death. Both concepts are related to a forewarning of the impending loss. Anticipatory grief has been suggested to be grief work before the loss, which would improve bereavement outcome, but recent studies indicate a negative impact. Hence, this review systematically investigates key issues relating to anticipatory grief and preparedness for the death, definitions, measurement tools, and potential effects on caregiver outcome. The assumptions that grief work before the loss would alleviate bereavement outcome was not confirmed. Thus, the concept of anticipatory grief is questioned. High preparedness was associated with improved caregiver outcome. Additional support should be given to caregivers with pre-loss grief and low preparedness. <http://goo.gl/kvj7hz>

**"It's like being a member of a club I didn't want to join." Reflections on a support group for bereaved dads**

*BEREAVEMENT CARE*, 2015;34(3):92-98. We know very little about dads' experiences of grief, and still less about the efficacy and impact of groups specifically set up to support them. This article is one attempt to address these gaps in knowledge and understanding, through consideration of a dads' group at Helen & Douglas House [Oxford, England]. The authors offer a different perspective on dads' grief and on groups for bereaved dads. The dads themselves powerfully articulate the extreme nature of their losses, explaining "nothing can solve the problem." On the other hand, they also stress that, within this context, the tiny improvements they feel and experience make coming to the group worthwhile and important. <http://goo.gl/yo8IUr>

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

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(1):15-19. 'Anticipatory grief: An evidence-based approach.' This article reviews the concept of anticipatory grief, explores various assessment tools, and offers communication-based management strategies. Key nursing implications are also discussed. <http://goo.gl/fECiIt>



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

### **GP workforce crisis set to undermine palliative care...**

GP | Online – 14 January 2016 – British Medical Association leaders have urged all U.K. governments to prioritise end-of-life care after research by the union found current provision – although “excellent” in some areas – “does not match expectations” of either doctors or the public.<sup>1</sup> Communication between primary and secondary care must be overhauled to improve patients’ experiences of palliative care (PC), the researchers found. In a series of interviews with patients and healthcare workers, they found that poor communication made it difficult to plan and co-ordinate care across healthcare sectors. Some GPs said they had not received adequate training on how to handle the dying process with patients and felt “uncomfortable” having to give uncertain answers on the timescale of life expectancy and fully meeting patients’ needs. The study suggested that the primary care role in delivering PC can be “unclear” in some areas, leading to inconsistencies across the country. It warned that continued provision of PC in the community – most patients’ preferred environment – would become much more challenging should GP workforce and workload problems worsen. <http://goo.gl/Z3QkYL>

1. ‘End-of-life care and physician-assisted dying,’ British Medical Association, January 2016. <http://goo.gl/IR5KmY>

### **Experience in strategic networking to promote palliative care in a clinical academic setting in India**

*INDIAN JOURNAL OF PALLIATIVE CARE*, 2016;22(1):3-8. Palliative care (PC) in low and middle-income countries is a new discipline, responding to a greater patient need than in high-income countries. By its very nature, PC as a specialty has to network with other specialties to provide quality care to patients. For any medical discipline to grow as a specialty, it should be well established in the teaching medical institutions of that country. Data show that PC is more likely to establish and grow in an academic health care institution. It is a necessity that multiple networking strategies are adopted to reach this goal. Ten different strategies were identified that helped with networking of PC in the institution. Networking is an essential strategy for the establishment of a relatively new medical discipline like PC in a developing and populous country like India, where the service is disproportionate to the demands. <http://goo.gl/4Y8Bwj>

### **Current status of palliative care services in Indonesia: A literature review**

*INTERNATIONAL NURSING REVIEW* | Online – 11 January 2016 – Facilitating factors supporting the provision of palliative care (PC) included: 1) A culture of strong familial support; 2) Government policy support; 3) Volunteering; and, 4) Support from regional organizations. Identified barriers to PC provision were a limited understanding of PC among healthcare professionals, the challenging geography of Indonesia, and limited access to opioid medications. There are facilitators and barriers that currently impact on the development of PC care in Indonesia. Strategies that can be implemented ... include training of nurses and doctors in the primary care sector, integrating PC in undergraduate medical and nursing curriculum, and educating family and community about basic care. Nurses and doctors who work in primary care can potentially play a role in supporting and educating family members providing direct care to patients with palliative needs. <http://goo.gl/6vCMmb>

Noted in Media Watch, 15 June 2015, #414 (p.4):

- INDONESIA | *The Jakarta Post* – 10 June 2015 – ‘**A defining moment.**’ Enhancing Palliative Care Practice, launched by the Singapore International Foundation, is jointly conducted with the Indonesia Cancer Foundation in Jakarta and the non-profit organization Rachel House, which has provided free palliative care (PC) for terminally ill poor children in Indonesia since 2006. As part of the program, Singapore’s PC specialists, led by Singapore International Volunteers team leader Ramaswamy Akhieswaran, will partner with medical professionals in Indonesia from ten hospitals in Jakarta to improve care for terminally ill patients. <http://goo.gl/JekdTK>

**N.B.** Indonesia was ranked 53rd of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5>

## Emergency department-initiated palliative care in advanced cancer: A randomized clinical trial

*JAMA ONCOLOGY* | Online – 14 January 2016 – The authors found that initiating palliative care (PC) in the emergency department (ED) for patients with advanced cancer improved quality of life (QOL) and did not seem to shorten survival. Given the diversity of the ED population and its often limited access to specialty care, this is an important place to initiate PC consultation. The impact on depression, hospital days, ICU admission, and hospice is less clear, and better ways of measuring whether care plans are congruent with patient goals are sorely needed. <http://goo.gl/aCzv36>

### Related

- *JAMA ONCOLOGY* | Online – 14 January 2016 – ‘**The emergency department point of palliative care access for patients with advanced cancer.**’ It is important to define and test criteria for palliative care (PC) referral from the ED in daily clinical practice. It is also important to better understand the attitudes and beliefs of both ED physicians and primary oncology teams toward automatic PC referrals, as well as the level of adherence to this process when implemented in regular clinical care. It will also be important to understand the attitudes and adherence of patients when referred to outpatient PC from the ED. <http://goo.gl/RbBKCY>

### Selected articles on palliative care in the emergency department

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 August 2015 – ‘**Palliative care screening and assessment in the emergency department: A systematic review.**’ The authors have identified multiple studies demonstrating that screening and referral for palliative care consultation is feasible. They recommend a screening framework based on a synthesis of available evidence. [Noted in Media Watch, 7 September 2015, #426 (p.13)] <http://goo.gl/LbYL6Q>
- *PALLIATIVE MEDICINE* | Online – 29 January 2015 – ‘**What’s in a name? A qualitative exploration of what is understood by “palliative care” in the emergency department.**’ There are entrenched contradictions and tensions surrounding the term “palliative care” ... [and] ... confronting these is likely to require more than “re-branding,” and will promote better care for this vulnerable patient group... [Noted in Media Watch, 9 February 2015, #396 (p.11)] <http://goo.gl/nLdAKQ>
- *EMERGENCY MEDICINE AUSTRALASIA* | Online – 25 July 2013 – ‘**Do patients die well in your emergency department?**’ Only 49% of survey respondents believed that the emergency department provided good palliative care (PC), and 80% were unaware of international gold standard PC protocols. [Noted in Media Watch, 5 August 2013, #317 (p.7)] <http://goo.gl/i0i5so>

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

#### End-of-life care in the Hispanic community

*JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(1):53-59. The Hispanic population is the largest minority in the U.S. and is expected to continue growing.<sup>1</sup> In order to provide culturally congruent care, perspectives of health, illness, and death must be viewed through the patient’s cultural lens. Hispanic patients with life-limiting diseases are particularly vulnerable because of access barriers to adequate care and because they might have had past experiences with discrimination, felt misunderstood, or felt disrespected by medical staff. Nurses play an indispensable role in advanced care planning of Hispanic patients. Nurses are well positioned to provide the relevant information and initiate the appropriate discussion about end-of-life planning. The authors ... address the cultural background and uniqueness, societal values, and factors facilitating end-of-life-care decision-making process in the Hispanic community. Recommendations are provided to overcome the challenges in implementing culturally competent care. <http://goo.gl/TqFio4>

1. According to U.S. Census Bureau population estimates, as of 1 July 2013, there are roughly 54 million Hispanics living in the U.S., representing approximately 17% of the country’s total population, making people of Hispanic origin the nation’s largest ethnic or race minority.

Cont.

Noted in Media Watch, 1 June 2015, #412 (p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 May 2015 – ‘**Education intervention “Caregivers Like Me” for Latino family caregivers improved attitudes toward professional assistance at end-of-life care.**’ This study explores the ability of a culturally sensitive and case-based education intervention to improve knowledge and attitudes regarding end-of-life resources among Latino caregivers. <http://goo.gl/0yeH0Y>

Noted in Media Watch, 7 October 2013, #326 (p.3):

- U.S. (California) | *New America Media* – 2 October 2013 – ‘**Why are Latinos not using palliative and hospice care?**’ Without change, aging Latinos are reaching the end of their lives unprepared spiritually or financially. Experts believe that the shift needs to happen from within the community, while others say it is a matter of poor cultural sensitivity from service providers. <http://goo.gl/5fYnIA>

### **Physicians’ recognition of death in the foreseeable future in patients with intellectual disabilities**

*JOURNAL OF INTELLECTUAL DISABILITY RESEARCH* | Online – 12 January 2016 – The authors aimed to explore when, based on which information sources and signals, physicians recognised that a patient with intellectual disabilities (ID) would die in the foreseeable future. Insights may help in identifying patients in need of palliative care (PC). More than 20% of physicians [i.e., survey respondents] foresaw death not until the last week of life. In 30% of all patients, they did not discuss the start of the PC phase until the last week. The most reported information sources based on which physicians foresaw death were the physicians themselves and professional caregivers. The authors found 40 different signals that lead to physicians’ foreseeing death. These were not only medical signals but also behavioural and physical signals. <http://goo.gl/yp8GdW>

Noted in Media Watch, 7 December 2015, #439 (p.13):

- *RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2016;49-50:47-59. ‘**Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?**’ The authors found that adults with intellectual disabilities (ID) had a significantly poorer understanding of the concept of death, knew much less about – and were less self-determined about – end-of-life (EOL) planning, but reported greater fear-of-death. The authors demonstrate, for the first time, the feasibility of assessing EOL planning and fear-of-death among adults with ID. <http://goo.gl/npKngs>

### **What are palliative care physicians for adults taught on palliative care for children? Paediatric aspects in palliative care curricula for adults**

*KLINISCHE PÄDIATRIE*, 2016;228(1):35-41. Children suffering from life limiting diseases are frequently cared for by adult palliative care teams due to missing paediatric structures in that field. However, it is questionable whether curricula for physicians comprehensively cover issues of paediatric palliative care (PaedPC). Inter-professional or medical palliative care curricula (PCC) were identified by an extensive literature review in German and English... Worldwide 30 PCC were identified, with only 15 curricula mentioning any PaedPC issues. Of those 15 curricula, up to 22 PaedPC topics were highlighted in each. In 10 or more PaedPC following topics were highlighted: 1) Grief and bereavement in family; 2) Parents and siblings; 3) Communication with children; 4) Paediatric malignancies; 5) Pain management in PPC; and, 6) Pharmacology. In the majority of PCC curricula where PaedPC issues were identified the following topics were mentioned: 1) Grief and bereavement in the family; 2) Parents and siblings; 3) Communication with children; 4) Paediatric malignancies; 5) Paediatric pain management; and, 6) Pharmacology. The variability of inclusion of PaedPC issues and the lack of depth and standardisation of knowledge, skills and attitudes in PaedPC issues included in PCC curricula is not sufficient to guide adult palliative care physicians in their clinical work with children suffering from life limiting diseases. <https://goo.gl/eEDqve>

Cont.

## Related

- *NARRATIVE INQUIRY IN BIOETHICS*, 2015;5(3):251-269. **‘Physician religion and end-of-life pediatric care: A qualitative examination of physicians’ perspectives.’** The authors conducted two rounds of narrative interviews to examine pediatric physicians’ perspectives of how their religious/spiritual beliefs affect end-of-life communication and care. The majority of participants suggested that religion/spirituality played a role in their practice of medicine and communication with parents in a myriad of ways and to varying degrees. Participants used their religious/spiritual beliefs to support families’ spirituality, uphold hope, participate in prayer, and alleviate their own emotional distress emerging from their patients’ deaths. <http://goo.gl/ZnphzF>

## Treatment preferences at the end-of-life in Parkinson’s disease patients

*MOVEMENT DISORDERS CLINICAL PRACTICE* | Online – 9 January 2016 – Few studies have been performed on palliative care in Parkinson’s disease (PD). This study was undertaken to understand treatment preferences of PD patients toward end-of-life care. Parkinson’s disease patients were more likely to agree to high-burden care with a poor outcome compared to controls. Among PD patients, race, marital status, religious status, knowledge about PD, and severity of motor impairment significantly influenced their end-of-life treatment preferences. <http://goo.gl/suqShJ>

Noted in Media Watch, 30 March 2015, #403 (p.11):

- *CURRENT NEUROLOGY & NEUROSCIENCE REPORTS* | Online – 22 March 2015 – **‘Palliative care for Parkinson’s disease: Has the time come?’** Although Parkinson’s disease is traditionally viewed as a movement disorder which affects quality of life, recent literature has revealed an increased mortality, a high burden of difficult-to-manage non-motor symptoms, high caregiver distress, and a high utilization of medical services especially in the last year of life. <http://goo.gl/09pTbj>

Noted in Media Watch, 15 July 2013, #314, (p.11):

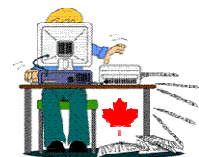
- *PALLIATIVE MEDICINE* | Online – 9 July 2013 – **‘Palliative care for Parkinson’s disease: A summary of the evidence and future directions.’** Despite calls for improved access to palliative care (PC) for people with Parkinson’s disease, services have been slow in developing. Obstacles include poor understanding and recognition of PC needs, the role for specialist PC services, and an agreed structure for sustainable PC provision. An integrated model of care is discussed. <http://goo.gl/dN4FfK>

## A systematic review of evidence for end-of-life communication interventions: Who do they target, how are they structured and do they work?

*PATIENT EDUCATION & COUNSELING*, 2016;99(1):3-16. A substantial number of end-of-life (EOL) communication interventions have been evaluated. These have particularly targeted health care providers in cancer settings, though patient, caregiver and multi-focal interventions have also been evaluated. While some interventions were efficacious ... most evidence was from less robust studies. While additional interventions targeting patients and caregivers are needed, multi-focal interventions may more effectively remove barriers to EOL communication. Healthcare professionals may still derive useful insights into effective approaches to EOL communication if appropriate caution is exercised. <http://goo.gl/MiRfdi>

### [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>



## An international consensus definition of the wish to hasten death and its related factors

*PLOS ONE* | Online – 4 January 2016 – The desire for hastened death or wish to hasten death (WTHD) that is experienced by some patients with advanced illness is a complex phenomenon for which no widely accepted definition exists. This lack of a common conceptualization hinders understanding and cooperation between clinicians and researchers. Following an exhaustive literature review, a modified nominal group process and an international, modified Delphi process were carried out. The nominal group served to produce a preliminary definition that was then subjected to a Delphi process in which 24 experts from 19 institutions from Europe, Canada and the U.S. participated. Delphi responses and comments were analysed using a pre-established strategy. All 24 experts completed the three rounds of the Delphi process, and all the proposed statements achieved at least 79% agreement. Key concepts in the final definition include the WTHD as a reaction to suffering, the fact that such a wish is not always expressed spontaneously, and the need to distinguish the WTHD from the acceptance of im-

pending death or from a wish to die naturally, although preferably soon. The proposed definition also makes reference to possible factors related to the WTHD. <http://goo.gl/kXTJQk>

### Final definition of the WTHD and its related factors

The WTHD is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon.

The WTHD may arise in response to one or more factors, including physical symptoms (either present or foreseen), psychological distress (e.g., depression, hopelessness, fears, etc.), existential suffering (e.g. loss of meaning in life), or social aspects (e.g., feeling that one is a burden).

### Selected articles on the desire to hastened death

- *PSYCHO-ONCOLOGY* | Online – 16 September 2015 – ‘**Desire for hastened death: How do professionals in specialized palliative care react?**’ Desires for hastened death (DHD) are prevalent in terminally ill patients. Studies show that health professionals (HP) are often underprepared when presented with DHD. HPs in specialized palliative care (SPC-HP) often encounter DHD. Narrative interviews were conducted with 19 SPC-HPs at four German University Hospitals. Twelve response categories and six corresponding functions were identified. [Noted in Media Watch, 21 September 2015, #428 (p.15)] <http://goo.gl/gU8vw3>
- *PALLIATIVE MEDICINE* | Online – 23 March 2015 – ‘**The desire to hasten death: Using grounded theory for a better understanding – “When perception of time tends to be a slippery slope.”**’ Patients [i.e., study participants] expected health professionals to listen to and respect their experiences. Emerging hypotheses: a) Patients try to balance life time and anticipated agony, and the perception of time is distressing in this balancing act; b) Anticipated images of agony and suffering in the dying process occur frequently and are experienced by patients as intrusive; c) Patients expressing a desire to hasten death are in need of more information about the dying process; and, d) Patients wanted their caregivers to listen to and respect their wish to hasten death, and they did not expect the caregivers to understand this as an order to actually hasten their death. [Noted in Media Watch, 30 March 2015, #403 (p.19)] <http://goo.gl/Ni8cLp>
- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. ‘**Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.**’ Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a desire to die statement, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. Where the relevant literature was lacking, the recommendations were drafted by the authors (clinicians and/or academics from the following disciplines: nursing, medicine, psychiatry, psychology, sociology, aged care and theology), based on their expert opinion. Strategies for advancing the evidence base for the maturation of guidelines in this area are offered. [Noted in Media Watch, 17 March 2014, #349 (p.16, under ‘Worth Repeating’)] <http://goo.gl/SwYhiG>

## Developing death literacy

*PROGRESS IN PALLIATIVE CARE* | Online – 8 January 2016 – Positioned within a public health framework, death literacy is considered an outcome of people’s experiences of and learnings about death and dying. Death literacy also appears to be a resource that individuals and communities can use for their own benefit strengthening their capacity for future caring. This purpose of this paper is to explore the concept of death literacy using the evidence from a 6-year research project. We do this by examining how it corresponds to, and differs from, existing concepts and practices such as death education, health literacy, and community development. The authors’ aim is to introduce new thinking into public health approaches to palliative care (PC), offer practice development pathways in this arena and propose that death literacy offers a useful conceptual framework for both describing and understanding the outcomes of a public health approach to PC. <http://goo.gl/78usHf>

### Related

- *PROGRESS IN PALLIATIVE CARE* | Online – 11 January 2016 – ‘**Going public: Reflections on developing the *DöBra* research program for health-promoting palliative care in Sweden.**’ Public health approaches to end-of-life research and care are relatively rare in Sweden, and health-promoting palliative care (HPPC) remains a foreign concept for most. The authors recently consolidated their HPPC endeavors into a cohesive research program, *DöBra*, to promote constructive change and awareness to support better quality of life and death among the general population, in specific sub-groups, and in interventions directed to professional groups caring for dying individuals, their friends and families. <http://goo.gl/RrNmwh>

### [Media Watch: Online](#)

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/qeiOX9>

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

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

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

#### **Asia**

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

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

#### **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>

## Worth Repeating

### **Patient navigation: A culturally competent strategy to address disparities in palliative care**

*JOURNAL OF PALLIATIVE MEDICINE*, 2007;10(5):1023-1028. There is growing acceptance and increasing application of patient navigation in the care of underserved populations. Navigators (also called *promotoras*, *comadres*, ambassadors, community health workers, lay health workers) work with patients and families to empower them to overcome barriers in the health care system and enjoy better health and health care. The roles of navigator vary across programs but usually include some degree of case management, patient education, social work, and advocacy. However, to the best of the authors' knowledge, patient navigators have not been utilized in palliative care (PC). In this paper they describe patient navigation in the traditional medical model and then illustrate how the patient navigator model applies to PC, using as an example their recently funded project to demonstrate the feasibility of a patient navigator to improve end of life outcomes for seriously ill Latinos. <http://goo.gl/yIH7h>

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