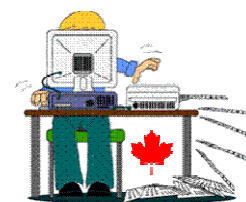


## Media Watch...

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 fact that the highest savings were in pharmacy and laboratory services suggests that unnecessary labs and medications are discontinued in an effort to improve patient care and quality of life while reducing costs during end-of-life care.*

*'University of Texas Southwestern's palliative care program: Measurable patient impact and cost-savings' (p.11), in *Journal of Pain & Palliative Care Pharmacotherapy*.*

## U.S.A.

### As death approaches, older Indian Americans unprepared for the end

CALIFORNIA | *India West* (Leandro) – 12 June 2019 – Discomfort with end-of-life (EoL) care discussions is not uncommon among many older immigrants in the U.S. Many of them come from countries where palliative care (PC) ... and hospice care ... are foreign concepts. And, writing an Advanced Health Care Directive (AHCD) is virtually unheard of. It wasn't until 2006, following a strategic campaign led by Dr. Susan Block, a PC pioneer in Boston, that hospice and palliative medicine became a defined medical specialty in the U.S. In 2011, U.S. medical schools began offering it as a specialty. In India, the unflagging efforts of M.R. Rajagopal, a Kerala anesthetist and founder of Pallium India, have brought a sea change in the palliative and hospice care landscape, especially in Kerala, where community healthcare workers are getting

trained in PC. Until 2015, India was near the bottom of global rankings of accessibility of EoL care, according to the Worldwide Hospice Palliative Care Alliance, a London-based organization. <http://bit.ly/2MOP2is>

### Specialist Publications

**'Empathy and attending to patient religion/spirituality: Findings from a national survey of Muslim physicians'** (p.10), in *Journal of Health Care Chaplaincy*.

**'Integration of palliative care and infection management at end-of-life in U.S. nursing homes'** (p.11), in *Journal of Pain & Symptom Management*.



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## Hospices adapt to support patients without family caregivers

*HOSPICE NEWS* | Online – 12 June 2019 – Cultural changes to family dynamics and demographics may require hospices to adjust their care and business models to care for patients who have no family support. Since its inception, hospice has been centered on both the patient and family, not only through providing services to the family but also relying on them as an essential part of the patient care team. Patients often lack caregivers due to outliving their relatives, being childless, divorce, having no siblings, or changes in geographic mobility. Few hospices can maintain round-the-clock care for patients in their homes, thus a lack of family caregivers can contribute to increased hospitalizations or nursing home admissions, as well as create ethical and legal challenges. Many of these patients have limited decision-making capacity and need assistance making healthcare choices, including decisions regarding hospice enrollment. A 2014 study found that older adult patients without family support, often called “unbefriended,” often do not enroll in hospice due to inadequate state policies governing third-party medical decisions for these patients.<sup>1</sup> With 1.4 million patients in hospice care and approximately 4% of older adults unbefriended, hospices can expect to see more of these patients as the population ages and hospice utilization continues to rise, according to the American Bar Association’s Commission on Law & Aging. <http://bit.ly/2WDGqjt>

1. ‘Patients who lack capacity and lack surrogates: Can they enroll in hospice?’ *Journal of Pain & Symptom Management*, published online 4 April 2014. [Noted in 14 April 2014 issue of Media Watch (#353, p.11).] **Full text:** <http://bit.ly/2F5G5v0>

Noted in Media Watch 5 February 2018 (#549, p.9):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 1 February 2018 – ‘**Medical decision-making for adults who lack decision-making capacity and a surrogate: State of the science.**’ Findings include: 1) Various terms are used to refer to adults who lack decision-making capacity and a surrogate; 2) The number of unbefriended adults is sizable; 3) Approaches to medical decision-making for this population in healthcare settings vary; and, 4) Professional guidelines and laws to address the issues related to this population are inconsistent. **Abstract:** <http://bit.ly/31sPari>

Noted in Media Watch 22 January 2018 (#547, p.11):

- *CANADIAN JOURNAL ON AGING* | Online – 17 January 2018 – ‘**Going it alone: A scoping review of unbefriended older adults.**’ The purpose of this study was to review the peer-reviewed and grey literature to determine the scope of available research on unbefriended older adults in Canada and the U.S. The authors found limited research examining unbefriended older adults. No Canadian studies or reports were located. These findings demonstrate a stark scarcity of studies on unbefriended older adults. **Abstract:** <http://bit.ly/2wSHuQQ>

### Crossroads of Grief Project – Grieving or Bereaved Children: Literature Review (2015-2018)



The Children & Youth Grief Network of Peel Region (Ontario, Canada) recently published a review of the literature focused on the many different aspects of grief and bereavement among children and young people. The main focus is on evidence-based studies published in peer-reviewed journals, reflecting current thinking on the many issues identified. **Download/view at:** <http://bit.ly/2QZBaAs>

## Never say “die”: Why so many doctors won’t break bad news

*KAISER HEALTH NEWS* | Online – 12 June 2019 – Robust research shows that doctors are notoriously bad at delivering life-altering news, said Dr. Anthony Back, an oncologist and palliative care (PC) expert at the University of Washington... The poor delivery of [a patient’s] diagnosis reflects common practice in a country where Back estimates that more than 200,000 doctors and other providers could benefit from communication training. Too often, doctors avoid such conversations entirely, or they speak to patients using medical jargon. They frequently fail to notice that patients aren’t following the conversation or that they’re too overwhelmed with emotion to absorb the information, Back noted in a recent article.<sup>1</sup> “[Doctors] come in and say, ‘It’s cancer,’ they don’t sit down, they tell you from the doorway, and then they turn around and leave,” he said. That’s because for many doctors, especially those who treat cancer and

other challenging diseases, “death is viewed as a failure,” said Dr. Brad Stuart, a PC expert and chief medical officer for the Coalition to Transform Advanced Care... They’ll often continue to prescribe treatment, even if it’s futile, Stuart said. It’s the difference between curing a disease and healing a person physically, emotionally and spiritually, he added. <http://bit.ly/2X7DtHg>

### Specialist Publications

‘Advanced cancer patients’ understanding of prognostic information: Applying insights from psychological research’ (p.9), in *Cancer Medicine*.

‘Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence’ (p.9), in *Palliative Medicine*.

1. ‘Training clinicians with communication skills needed to match medical treatments to patient values,’ *Journal of the American Geriatric Society*, 2019;67(S2):S435-S441. Full text: <http://bit.ly/2la3XQ8>

## Assisted (or facilitated) death

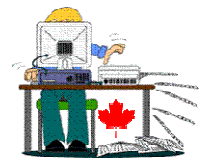
Representative sample of recent news media coverage:

- MAINE | Courthouse News Service (Augusta) – 12 June 2019 – ‘**Maine governor signs bill legalizing assisted suicide.**’ Maine officially became the eighth state to legalize assisted suicide when Governor Janet Mills signed the practice into law after the state Senate sent it to her desk last week. Maine’s Death with Dignity Act establishes the procedures to allow those with a terminal illness and a short time to live to be prescribed medication to end their life. Along with the law, Mills signed an executive order that requires the Maine’s Department of Health & Human Services to track instances of those choosing to end their life, in order to ensure that certain members of different socioeconomic classes aren’t disproportionately killing themselves. <http://bit.ly/2MLio1k>
- U.S. | *The Daily Wire* – 11 June 2019 – ‘**American Medical Association votes on assisted suicide.**’ Despite a fierce push from so-called “death with dignity” advocates, one of the largest and most influential medical organizations in the nation, the American Medical Association (AMA), voted to retain its position against assisted suicide and euthanasia measures. On direction from a Council on Ethical & Judicial Affairs report, the AMA voted 65-35 in favor of treating the terminally ill... <http://bit.ly/2X1AFv3>

**N.B.** ‘Physician assisted suicide: Code of Medical Ethics Opinion 5.7,’ American Medical Association, 2019. Download/view at: <http://bit.ly/2WD0brk>

### 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://bit.ly/2RPJy9b>



## International

### End-of-life care in England

#### **End-of-life care not “culturally competent”**

U.K. (England) | BBC News (London) – 1 June 2019 – A study has been launched to try to boost the number of black and Asian people using end-of-life care (EoLC) services. Figures suggest black and Asian patients are 20% less likely to seek palliative help than their white counterparts. There is concern they feel excluded by the way the services are currently set up. The researchers, from Leicester, plan to use their results to develop national guidance to improve access. Diagnosed with lymphoma in 2017, Dalbagh Singh visits his local hospice in Luton for weekly treatment. But many Sikh families simply would not consider hospice care, he says. Differences in culture, religious practices and language barriers have been cited as reasons why Asian people might be reluctant to access EoLC. Some doctors are also reluctant to offer services because they may not fully understand a patient’s needs or fear they may cause offence. The research team, based at the Loros hospice, will gather evidence from black and Asian patients, families, caregivers, and health professionals from across the Midlands over the next 30 months. <https://bbc.in/2KiPLXe>

#### **What support do carers need when they are facing bereavement?**

U.K. (England) | National Bereavement Alliance – 14 June 2019 – ‘Care after Caring: Supporting family carers facing and following bereavement,’ commissioned by National Health Service England’s Commitment to Carers programme, shares good practice and ideas ... things that can be put in place before the death, to improve outcomes in bereavement. Others are ways of improving support after the death, to make it more sensitive to the lasting impact of caring. The report draws on research, policy and consultations with former carers and those supporting them, to lay out a series of six aspirations for local areas and services to get the right support in place at the right time. The report also in-

cludes 12 examples of local good practice in supporting carers facing and following bereavement. <http://bit.ly/2Rpwg01>

#### **Specialist Publications**

**‘Helping healthcare providers and staff process grief through a hospital-based program’** (p.6), in *American Journal of Nursing*.

**‘Grief: A brief history of research on how body, mind, and brain adapt’** (p.7), in *Psychosomatic Medicine*.

#### **More people choosing to die at home in Nottinghamshire**

U.K. (England) | CHAD (Mansfield) – 11 June 2019 – Dying at home is becoming more common in Nottinghamshire, according to official figures. The latest data from Public Health England reveals that about 24% of the deaths registered in 2017 occurred at home, up from 22% five years earlier. The data identifies the four most common places of death as hospitals, care homes, hospices and homes. The number of people dying at home has risen over the last five years – from 7,593 in 2012 to 2,033 in 2017. But the biggest chunk of deaths in Nottinghamshire occur in hospitals – 47 in total in 2017. About 24% of the deaths in the area occurred at care

home facilities while 4% took place at hospices. <http://bit.ly/2MIAIbk>

#### **Specialist Publications**

**‘Going home to die from critical care: A case study’** (p.12), in *Nursing in Critical Care*.

**‘What socio-economic factors determine place of death for people with life-limiting illness? A systematic review and appraisal of methodological rigour’** (p.12), in *Palliative Medicine*.

## China to promote end-of-life care services

CHINA | Xinhua (Beijing) – 10 June 2019 – China has begun to pilot an end-of-life care (EoLC) program in Shanghai as well as in over 70 other cities and municipal districts... The pilot program was first launched in five cities and municipal districts, including Haidian District in Beijing, Putuo District in Shanghai and Changchun City in the northeastern province of Jilin, in 2017. The National Health Commission released a circular on the pilot program in May, calling for more research and investigations, recruitment of more talent as well as improved mechanisms to serve the program... EoLC, which is not yet common in China, provides palliation to terminally or seriously ill patients and meets their physical, mental and spiritual needs, aiming to help them die with more comfort and dignity. A total of 283,000 patients received EoLC across the country in 2018... China had about 170 million people aged 65 or above as of the end of 2018, which accounted for nearly 12% of its total population. <http://bit.ly/2F1GSNz>

**N.B.** Additional articles on EoLC in China noted in past issues of Media Watch: 3 June and 18 March 2019 (#616 and #606, respectively, and 22 October 2018 (#586, p.7).

## End-of-life care [in England] is “postcode lottery”

U.K. (England) | *The Daily Express* (London) – 9 June 2019 – Baroness Iora Finlay’s [proposed] Bill will require clinical commissioning groups across England to ensure that high-quality, specialist palliative care (PC) services are available for everyone who needs them. She said: “This is an urgent healthcare issue, with recent projections [showing] that PC needs will rise by 42% in the next 25 years.” Baroness Finlay, a doctor who is now deputy speaker of the House of Lords, is concerned by “failures in care planning and access to out-of-hours services” and says the standard of care for patients and their families varies greatly across the nation. She said: “There are an estimated 118,000 people a year in England who would benefit from PC but are not receiving it.” Baroness Finlay argues it would be “totally unacceptable not to provide maternity services” but the country has “people dying with complex needs with no specialist service available in their area.” Her Bill is intended to help people of all ages, but there is specific concern about the situation facing older people. Age UK claims that although the 65-plus population accounts for 85% of all deaths, older people are “often least likely to have access to specialist PC.” It states that while between 50-70% of people would prefer to die at home, “only 16.7% of deaths in people aged 85-plus occur at home.” <http://bit.ly/213vxhG>

### Recent news media coverage on funding issues impacting hospices in England

*The Guardian* – 15 June 2019 – ‘Cash crisis forces children’s hospices in England to limit respite care.’ <http://bit.ly/2WJrScW>

*Surrey Live* – 9 June 2019 – ‘Surrey hospice chiefs say financial and recruitment pressures could lead to closure of units.’ <http://bit.ly/2XyRqLa>

*The Shropshire Star* – 4 June 2019 – ‘Shock for families as children’s hospice set to close.’ <http://bit.ly/2WljMw7>

*The Shropshire Star* – 14 May 2019 – ‘£250,000 cut to Telford hospice’s grant was “necessary,” says health boss.’ <http://bit.ly/30fywLf>

ITV News – 7 May 2019 – ‘U.K. hospices face funding crisis as one in three forced to cut end-of-life services.’ <http://bit.ly/3071bSA>

*The Daily Mirror* – 28 January 2019 – ‘Hospices could face closure over £30 million Tory “stealth tax” levy on owners.’ <http://bit.ly/2B6y8Uu>

*The Shields Gazette* – 21 January 2019 – ‘St. Clare’s Hospice closes after more than 30 years.’ <http://bit.ly/213YvAj>

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Closing the Gap Between Knowledge & Technology  
<http://bit.ly/2DANDFB>

Noted in Media Watch 23 July 2018 (#573, p.3):

- U.K. (England) | *The Daily Mail* (London) – 17 July 2018 – ‘**Dying patients are being neglected by councils, with budgets for end-of-life care as low as £52 per person.**’ Dying patients are still being neglected by councils. End-of-life (EoL) care is being prioritised by only 4% of town halls in England, according to analysis by experts at King’s College London.<sup>1</sup> Councils, which have responsibility for social care, face increasing numbers of elderly people needing EoL support. Demand is set to increase 42% by 2040. Quality of care and resources varied hugely around the country, with budgets ranging from £52 to £2,329 per patient per year for palliative care. <https://dailym.ai/2EYKbF4>

1. ‘Is end-of-life care a priority for policymakers? Qualitative documentary analysis of health-care strategies,’ *Palliative Medicine*, published online 17 July 2018. **Full text:** <http://bit.ly/2ZnGeBR>

**N.B.** Selected articles on access to palliative and EoL care in the U.K. noted in this issue of Media Watch.

Noted in Media Watch 6 March 2017 (#502, p.5):

- U.K. (England) | BT.com News (London) – 1 March 2017 – ‘**Researchers warn of postcode lottery in care for the dying.**’ Dying people are being left with inadequate round-the-clock pain relief and poor access to specialist help, according to new research.<sup>1</sup> They are caught in a postcode lottery which affects whether their families are able to secure proper National Health Service (NHS) end-of-life care on weekends and during the night. In some parts of England, NHS bosses only provide a telephone advice line to cater for people in their last days of life. Meanwhile, others have full palliative care teams with expertise in areas such as controlling cancer pain or lessening distress. <http://bit.ly/2ZgZDnW>

1. ‘Commissioning of specialist palliative care services in England,’ *BMJ Supportive & Palliative Care*, published online 28 February 2017. **Full text:** <http://bit.ly/2XyQXIU>

## Specialist Publications

### Helping healthcare providers and staff process grief through a hospital-based program

*AMERICAN JOURNAL OF NURSING* | Online – 7 June 2019 – This study investigated the feasibility and effectiveness of offering an intensive bereavement support program to hospital employees in a large academic health system. Between 2013 and 2017, Montefiore Health System [Bronx, New York] held nine Healing Loss workshops, serving 198 employees from diverse professions. Participants described multiple benefits, including being able to grieve more effectively, accessing support, and learning new tools for healing and self-care. Participants described the workshop experience as unique, cathartic, and life changing. The sustainability of the Healing Loss initiative during the four years of the study, together with strong feedback from

participants, indicates bereavement support for hospital employees is both feasible and beneficial. **Abstract:** <http://bit.ly/2KMrCrD>

### Specialist Publications

‘The association between quality measures of medical university press releases and their corresponding news stories. Important information missing’ (p.15), in *Plos One*.

‘The war to free science: How librarians, pirates, and funders are liberating the world’s academic research from paywalls’ (p.15), in *Vox Media*.

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Would this article be of interest to a colleague?

## Related

- *PSYCHOSOMATIC MEDICINE* | Online – 11 June 2019 – ‘**Grief: A brief history of research on how body, mind, and brain adapt.**’ Morbidity and mortality following the death of a loved one has long been a topic of research. Early researchers characterized somatic and psychological symptoms and studied immune cell changes in bereaved samples. More recent research has repeatedly demonstrated increased rates of morbidity and mortality in bereaved samples, as compared to married controls, in large epidemiological studies. Recent developments also include the development of criteria for prolonged grief disorder (also termed complicated grief). **Abstract:** <http://bit.ly/2KKRh3C>

## **Serious Illness Care Programme U.K.: Assessing the “face validity,” applicability and relevance of the serious illness conversation guide for use within the U.K. healthcare setting**

*BMC HEALTH SERVICES RESEARCH* | Online – 13 June 2019 – When doctors have honest conversations with patients about their illness and involve them in decisions about their care, patients express greater satisfaction with care and lowered anxiety and depression. The Serious Illness Care Programme (the Programme), originally developed in the U.S, promotes meaningful, realistic and focused conversations about patient’s wishes, fears and worries for the future with their illness. The Serious Illness Conversation Guide provides a framework to structure these conversations. Use of the guide has the potential to benefit patients, facilitating a ‘person-centred’ approach to these important conversations, and providing a framework to promote shared decision making and care planning. Further research is ongoing, to understand the impact of these conversations on patients, families and clinicians and on concordance of care delivery with expressed patient wishes. **Full text:** <http://bit.ly/31Bg0xB>

## **A systematic review of the effects of advance care planning facilitators training programs**

*BMC HEALTH SERVICES RESEARCH* | Online – 7 June 2019 – Communication and decision-making about the goals of care are identified by seriously ill hospitalized patients and their families as important targets for improvement, if the quality of end-of-life care (EoLC) is to be enhanced. Although a significant proportion of deaths occur in non-palliative care settings, clinicians in acute settings have low involvement in advance care planning (ACP) discussions. The importance of ACP in clarifying patients’ values and respecting their wishes or autonomy is clear. Nurses have a valuable role in leading ACP implementation and in creating system-wide cultural changes to improve EoLC. This systematic review found that training for healthcare professionals in ACP had positive effects on their knowledge, attitude and skills. However, there is a lack of high quality randomized controlled trials to evaluate the effectiveness of ACP facilitator training programs for nurses working in non-palliative care hospital settings. By evaluating the effectiveness of the training programs, the possibilities of such programs in clinical practice will be explored and recommendations for further development of ACP training program will be made, to enhance quality EoLC in non-palliative care hospital settings. The use of decision aids and advanced technology, instructional sessions with role play, training content focused on ACP communication skills and the needs and experience of patient in the ACP process, and a values-based ACP process are all those factors that made the ACP training programs effective. **Full text:** <http://bit.ly/2WW70U2>

## Related

- *PALLIATIVE MEDICINE* | Online – 14 June 2019 – ‘**Do published patient decision aids for end-of-life care address patients’ decision-making needs? A systematic review and critical appraisal.**’ Twenty-two studies described patient needs, and seven end-of-life patient decision aids were identified. Patient needs were categorised, resulting in 48 “addressable” needs. Mapping needs to patient decision aid content showed that 17 patient needs were insufficiently addressed by current patient decision aids. The most substantial gaps included inconsistent acknowledgement, elicitation and documentation of how patient needs varied individually for the level of information provided, the extent patients wanted to participate in decision-making, and the extent they wanted their families and associated healthcare professionals to participate. **Abstract:** <http://bit.ly/2lhYFlz>

Cont.

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 10 June 2019 – ‘**Advance care planning in different settings for people with dementia: A systematic review and narrative synthesis.**’ Of 4,772 articles returned by searches, 30 met the authors’ inclusion criteria, testing interventions in nursing home, community and acute care settings. Only 18 interventions directly involved the person with dementia, with the remainder focusing on surrogate decision-makers. In all settings, interventions were found effective in increasing advance care planning (ACP) practice. In nursing homes, ACP was found to influence care and increase the concordance between end of life wishes and care provided. Interventions in the community were found to improve patient quality of life but were not shown to influence concordance. **Abstract (w. list of references):** <http://bit.ly/2Zl26Ob>

Noted in Media Watch 4 March 2019 (#604, p.13):

- *PALLIATIVE CARE: RESEARCH & TREATMENT*: Online – 27 February 2019 – ‘**Advance care planning in dementia: Recommendations for healthcare professionals.**’ The process of advance care planning in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision-making abilities. Family carers find themselves increasingly in a position where they need to inform, or directly make, decisions on behalf of the person with dementia. This article discusses the context and importance of a palliative care approach and recommends rationales and strategies for healthcare professionals to support families affected by dementia to better plan for their future care. **Full text:** <http://bit.ly/2Habdvd>

**N.B.** Additional articles on ACP, advance directives and end-of-life decision-making for people living with Alzheimer’s disease and other forms of dementia noted in 18 February 2019 issue of Media Watch (#602, pp.8-9).

### **Early release rules for prisoners at end of life may be “discriminatory,” say doctors**

*BRITISH MEDICAL JOURNAL* | Online – 12 June 2019 – Doctors have called for changes to the rules governing when terminally ill prisoners can be released early on compassionate grounds, amid concern that the current approach is discriminatory. Data obtained from the Ministry of Justice, shared with the *British Medical Journal*, indicate that prisoners in England and Wales at the end of life are more likely to be granted early release on compassionate grounds if they have cancer than if they have other conditions, say clinical researchers who examined the data. Under current legislation the secretary of state for justice can grant early release where there is a risk of harm to the prisoner from ongoing imprisonment, potential benefit through release, a low risk of recidivism, and adequate arrangements for safe care in the community. But, crucially, the prisoner’s death must be expected “very soon,” and HM Prisons & Probation Service considers this to be within three months. Jim Burtonwood, a palliative care specialist ... who led the research, said the current rules meant that timescales often became too tight for a successful application for early release if an acknowledgment of terminal decline was delayed or there was prognostic uncertainty. **Full text:** <http://bit.ly/2WEwEIO>

#### **Related**

- *BRITISH MEDICAL JOURNAL* | Online – 12 June 2019 – ‘**Early release rules for prisoners at end of life need reform.**’ Demographic changes among the prison population mean that deaths among prisoners in England and Wales are increasing; 204 prisoners died from natural causes in the 12 months ending March 2017, double the number a decade ago. Provision of palliative care for the increasingly aged prison cohort is challenging. Prisoners have the right to healthcare equal to that of any other patient, but not at the expense of risk of harm to society. Tensions inevitably arise in trying to respect the autonomy of people who have had their freedom curtailed by the state, especially when considering the preferred place of death of a prisoner. **Full text:** <http://bit.ly/2wPNF8B>

**N.B.** End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., (updated 20 May 2019) noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>



## **Advanced cancer patients' understanding of prognostic information: Applying insights from psychological research**

*CANCER MEDICINE* | Online – 14 June 2019 – In this literature review, the authors synthesize complementary findings from basic behavioral science and applied clinical research, which suggest that psychological factors can significantly influence both patients' clinical interactions and their prognostic understanding. For example, stress and emotion can affect cognition, which may shape how patients process complex medical information. Additionally, clinicians may be less likely to share prognostic information with distressed patients who, in turn, may be hesitant to ask about their prognosis for fear of the answer. Although traditional approaches for increasing advanced cancer patients' understanding focus on improving information delivery, these efforts may not be sufficient without corresponding interventions that assist patients in managing distress. Psychological barriers may limit opportunities for patients to fully understand their prognosis and to receive high quality of end-of-life care that is linked with an accurate understanding of their disease and treatment options. Failure to attend to patients' emotional distress may undermine efforts to improve medical communication. This underscores the importance of increased attention to the psychological factors that impede patients' comprehension of material shared in cancer clinic visits, in order to inform interventions that address patient distress both before and after receiving "bad news." Integrating findings from psychological research into prognostic discussions may not only improve advanced cancer patients' mental health, but may also promote their ability to make informed, value-consistent medical decisions. **Abstract (via PubMed):** <http://bit.ly/2ZnCBvB>

### **Related**

- *PALLIATIVE MEDICINE* | Online – 11 June 2019 – '**Communication between healthcare professionals and relatives of patients approaching the end-of-life: A systematic review of qualitative evidence.**' To improve communication, it is important to first identify how this is currently being accomplished. Seven themes were identified: 1) Highlighting deterioration; 2) Involvement in decision-making; 3) Post-decision interactional work; 4) Tailoring; 5) Honesty and clarity; 6) Specific techniques for information delivery; and, 7) Roles of different healthcare professionals (HCPs). Varied levels of family involvement in decision-making were reported. HCPs used strategies to aid understanding and collaborative decision-making, such as highlighting the patient's deterioration, referring to patient wishes and tailoring information delivery. **Abstract:** <http://bit.ly/2wKRzN>

## **Telemedicine in palliative care: Implementation of new technologies to overcome structural challenges in the care of neurological patients**

*FRONTIERS IN NEUROLOGY* | Online – 24 May 2019 – Telemedicine provides a possibility to deal with the scarcity of resources and money in the healthcare system. Palliative care (PC) has been suggested to be appropriate for an increasing number of patients with neurodegenerative disorders, but these patients often lack care from either PC or neurology. Since PC means a multidisciplinary approach it is meaningful to use PC structures as a basis. There exists no systematic access to neurological expertise in an outpatient setting. A successful link of two existing resources is shown in this project connecting the department of neurology of a university hospital [in Bavaria, Germany] with specialized outpatient PC teams. A video counselling system is used to provide expert care for neurological outpatients in a palliative setting. The authors' data provides strong evidence that the technical structure applied in this project allows a reasonable neurological examination at distance. Qualitative interviews indicate a major impact on the quality of work for the specialist PC teams and on the quality of care for neurological patients. **Full text:** <http://bit.ly/2R6fuCO>

### **Related**

- *PALLIATIVE MEDICINE* | Online – 12 June 2019 – '**Video consultations in palliative care: A systematic integrative review.**' Using video technology in palliative care (PC) has both advantages and disadvantages. However, evidence beyond the focus on specialized PC and patients with cancer is limited. Future research should focus on how and when video consultations might replace in-person specialized PC and video consultations in general PC, in low and middle income countries; and involve patients with a non-cancer diagnosis. **Abstract:** <http://bit.ly/2wQsHX4>

## Improving caregivers experience: Enhancing end-of-life care for residents

*INTERNATIONAL PRACTICE DEVELOPMENT JOURNAL* | Online – Accessed 13 June 2019 – Global demographic changes are resulting in an ageing population with increasingly complex needs and comorbidities. The nursing home sector will increasingly play a critical role in the care of people at the end of life (EoL). Education for staff in this sector is variable in nature, with little evidence of its impact on practice. The findings of this study confirm the strength of adopting a practice development approach to underpin a staff education programme. Integrating registered nurses and care assistants in the learning environment enhanced working relationships and translated to a more healthful workplace culture and enhanced person-centred EoL care. **Abstract:** <http://bit.ly/31vt5IG>

## Allied health clinicians' understanding of palliative care as it relates to patients, caregivers, and health clinicians: A cross-sectional survey

*JOURNAL OF ALLIED HEALTH*, 2019;48(2):127-133. The scope of hospice or palliative care (PC) has expanded since its inception, which has significant ramifications for the allied health (AH) workforce. Four themes were identified: 1) PC employs a client-centred model of care; 2) Acknowledgement of living whilst dying; 3) Interdisciplinary PC interventions provide active care in a range of domains; and, 4) Characteristics of PC teams and settings. AH clinicians plan an active role in physical, social, and psycho-spiritual care of PC patients and caregivers. Burgeoning numbers of PC patients in non-specialist PC settings require AH clinicians to develop skills and competencies to work with people who have advanced disease. **Abstract:** <http://bit.ly/2MQIWio>

## Empathy and attending to patient religion/spirituality: Findings from a national survey of Muslim physicians

*JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 10 June 2019 – Attending to patient religion and spirituality (R/S) generates controversy. Some worry that because physicians lack formal religious training they may overstep their expertise, while others argue that physicians who are attentive to patient R/S provide higher quality of care. The authors aimed to describe American Muslim physicians' perspectives and practices regarding R/S discussions, and how physician characteristics correlate with these. A questionnaire including measures of religiosity, empathy, and attitudes and behaviors toward R/S, was randomly administered to Islamic Medical Association of North America members. More empathetic physicians were more likely to inquire about patients' R/S, share their own religious ideas and experiences, and encourage patients in their own R/S beliefs and practices. More empathetic physicians also had greater odds of encouraging discontinuation of futile life-sustaining interventions. Respondents with higher empathy had greater odds of encouraging patients at the end-of-life to seek reconciliation with God, and seek the forgiveness of those they have wronged. In the context of R/S diversity among the patient and provider population, enhancing physician empathy may be key to attending to the health-related R/S needs of patients. **Abstract:** <http://bit.ly/2Wu2ibS>



Noted in Media Watch 4 March 2019 (#604, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 February 2019 – '**Assessing relationships between Muslim physicians' religiosity and end-of-life healthcare attitudes and treatment recommendations: An exploratory national survey.**' Attitudes of religious physicians toward end-of-life (EoL) care treatment can differ substantially from their non-religious colleagues. While there are various religious perspectives regarding treatment near the EoL, the attitudes of Muslim physicians in this area are largely unknown. This article attempts to fill in this gap by presenting American Muslim physician attitudes toward EoL care decision-making and by examining associations between physician religiosity and these attitudes. **Abstract:** <http://bit.ly/2Elbokd>

**N.B.** Additional articles on the Islamic perspective on EoL and EoL care noted in 5 & 12 February 2018 issues of Media Watch (#549, p.8 and #550, p.14, respectively).

## University of Texas Southwestern's palliative care program: Measurable patient impact and cost-savings

*JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 13 June 2019 – The purpose of this analysis was to measure the impact of palliative care (PC) services on hospital charges in the 5 days prior to death – the most expensive time of a patient's life – and identify hospital service categories and patient financial classes yielding the highest savings from PC. PC patients were defined as any patient who received at least one completed PC order. The final patient population included in the analysis ... was composed of mostly white, non-Hispanic males. The majority of the patients had five or fewer comorbidities, and the primary preexisting conditions seen among patients were cardiovascular diseases (36.0%) and cancer (23.4%). The hospital service categories yielding the highest mean savings were pharmacy (mean \$2,765) and labs (mean \$1,063). Financial classes with the greatest savings were Medicaid and charity/self-pay. Overall, there was a significant difference in charges between those that received a PC consult and those that did not. The fact that the highest savings were in pharmacy and laboratory services suggests that unnecessary labs and medications are discontinued in an effort to improve patient care and quality of life while reducing costs during end-of-life (EoL) care. PC services ease the cost burden of EoL services for low-income populations. **Abstract:** <http://bit.ly/2WCxMMZ>

**N.B.** Articles on drugs of questionable clinical benefit near the EoL noted in 10 June 2019 issue of Media Watch (#617, p.13).

## Organizing psychologists, behavioral scientists, and allied professionals: Formation of the Society of Behavioral Medicine's Palliative Care Special Interest Group

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 June 2019 – Palliative care (PC) spans many disciplines, including physicians, nurses, social workers, chaplains, and psychologists. While psychologists and other behavioral scientists have much to offer the field of PC in both clinical and research domains, they are underrepresented in PC professional organizations. The authors held the first meeting of the Palliative Care Special Interest Group at the Society of Behavioral Medicine's annual conference in March 2019. The meeting served as a mechanism for organizing psychologists involved in PC and improving their connections with allied professionals. **Abstract (w. link to references):** <http://bit.ly/2KKpfFK>



## Integration of palliative care and infection management at end-of-life in U.S. nursing homes

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 June 2019 – Integration of palliative care (PC) and infection management (IM), is a new concept that can help reduce burdensome treatments and improve quality of care for nursing homes (NH) residents at the end-of-life. A nationally representative sample of NHs was surveyed. 892 NH surveys were returned (49% response rate), 859 with complete data. Three integration factors were identified: 1) Patient involvement in care planning; 2) Formalized advance care planning; and, 3) Routine practices of integration. Integration is a distinct concept that is associated but different from PC and IM. Results of this study serve as a baseline assessment of integration in NHs. Continued refinement of the integration instrument is recommended as is studying if higher integration leads to better resident outcomes. **Abstract (w. link to references):** <http://bit.ly/2KNDzwS>

## Role of child life specialists in pediatric palliative care

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 June 2019 – Each year, more than 500,000 children in the U.S. cope with life-threatening conditions. Many are hospitalized for long periods for curative treatment and some remain in the hospital for end-of-life (EoL) care. Long inpatient stays lead to tremendous physical and emotional stress for both patients and their families and the management of the burden associated with these periods may be improved by support provided by a comprehensive pediatric palliative care team. The team has a holistic approach, coordinates many interdisciplinary services, and addresses the physical, emotional, social and spiritual issues that are often present at the EoL. **Abstract (w. link to references):** <http://bit.ly/2KJlxMf>

## Case report

### **Virtual reality: Endless potential in pediatric palliative care**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 June 2019 – Pediatric palliative care (PC) deals with the physical, psychosocial, and spiritual concerns of patients and their families. And to do this, clinicians must use all the tools at their disposal, including pharmacological and non-pharmacological modalities. Virtual reality is quickly becoming a useful tool in many areas of medicine, including surgical planning, simulation training, rehabilitation, and pain prevention and treatment. Recently it has been used in the adult PC population for symptom management, and memory and legacy creation. The authors present a case report for, what they believe to be, the first time in the pediatric PC population. **Abstract:** <http://bit.ly/2XbaeDz>

### **Palliative care for terminally ill individuals with borderline personality disorder**

*JOURNAL OF PSYCHOSOCIAL NURSING & MENTAL HEALTH SERVICES* | Online – 12 June 2019 – Individuals with borderline personality disorder (BPD) exhibit persistent patterns of instability in mood, impulse control, self-image, and interpersonal relationships. These issues complicate quality end-of-life care for this population and are of particular concern for hospice and palliative care (PC) nurses and healthcare providers. This article presents case studies of terminally ill individuals with BPD as a series of vignettes that present common clinical issues encountered by the PC team. Interventions suggested in the literature as well as approaches used by team members when working with terminally ill individuals with BPD are discussed. **Abstract:** <http://bit.ly/2XHrpJG>

### **Going home to die from critical care: A case study**

*NURSING IN CRITICAL CARE* | Online – 10 June 2019 – Much of the activity in critical care is complex but repetitive. In order to standardize care and maintain safety, delivery of care is often directed by protocols and care bundles. This case study will reflect on an instance where care transcended the standard protocol-directed path to be more individualized, creative and compassionate. Acts like these can be unique for the practitioners involved and require an element of positive risk taking, which happened here. It will look at the decision-making, planning and risk involved in preparing for a terminally ill patient, who was inotrope and high-flow oxygen dependent, to go home to have treatment withdrawn there instead of in the hospital. This was to fulfil his wish to die at home. In unpicking the circumstances where this positive risk taking led to the desired outcome and the relationship between safety, uncertainty and risk, three themes arose. These were the journey to safe uncertainty; decision-making with uncertain outcomes; and, the importance of robust human factors, particularly effective communication and inter-professional teamwork. If positive risk taking can result in enhanced outcomes for the patient, then the question of how this behaviour can be fostered and encouraged must be addressed. **Abstract:** <http://bit.ly/2XFeTKG>



#### **Related**

- *PALLIATIVE MEDICINE* | Online – 12 June 2019 – ‘**What socio-economic factors determine place of death for people with life-limiting illness? A systematic review and appraisal of methodological rigour.**’ Dying at home was to a high degree associated with better financial situation and living in rural areas. Furthermore, hospital death was associated with a high level of deprivation in the area of residence and being employed. Inequalities concerning place of death were found, and attention towards socio-economic inequality concerning place of death is necessary, especially in patients with a poor financial status, patients living in deprived and metropolitan areas and patients who are employed. Furthermore, the authors found a low degree of assessment for collinearity and adjustment of socio-economic variables. **Abstract:** <http://bit.ly/2R7zIS4>

## **Consumer and carer leadership in palliative care academia and practice: A systematic review with narrative synthesis**

*PALLIATIVE MEDICINE* | Online – 14 June 2019 – Contemporary health policies call for consumers to be part of all aspects of service planning, implementation, delivery and evaluation. The extent to which consumers are part of the systemic decision-making levels of palliative care (PC) appears to vary between and within services and organisations. Eleven studies met the authors' inclusion criteria and quality assessment. Consumers are currently involved in leadership of PC teaching, research and services. Findings highlight the benefits of consumer leadership in PC including more relevant, higher-quality services, teaching and research. Across the included studies, it was not clear the extent to which consumer leaders had influence in relation to setting agendas across the PC sector. The findings suggest that more could be done to support consumer leadership within PC. Academics and clinicians might improve the relevance of their work if they are able to more meaningfully partner with consumers in systemic roles in PC. **Abstract:** <http://bit.ly/2Xh60Ko>

## **Which outcome domains are important in palliative care and when? An international expert consensus workshop, using the nominal group technique**

*PALLIATIVE MEDICINE* | Online – 12 June 2019 – When capturing patient-level outcomes in palliative care (PC), it is essential to identify which outcome domains are most important and focus efforts to capture these, in order to improve quality of care and minimise collection burden. In all, 33 clinicians and researchers working globally in PC outcome measurement participated in an international expert consensus workshop. The domains of “overall wellbeing/quality of life,” “pain,” and “information needs/ preferences” are recommended for regular measurement, assessed using “phase of illness.” International adoption of these recommendations will help standardise approaches to improving the quality of PC. **Abstract:** <http://bit.ly/2X1Yqfn>

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- *PALLIATIVE MEDICINE* | Online – 12 June 2019 – ‘**A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale.**’ The Integrated Palliative Care Outcome Scale is a valid and reliable outcome measure, both in patient self-report and staff proxy-report versions. It can assess and monitor symptoms and concerns in advanced illness, determine the impact of healthcare interventions, and demonstrate quality of care. This represents a major step forward internationally for palliative care outcome measurement. **Abstract:** <http://bit.ly/2KHggMC>

## **Exploring demoralization in end-of-life cancer patients: Prevalence, latent dimensions, and associations with other psychosocial variables**

*PALLIATIVE & SUPPORTIVE CARE* | Online – 14 June 2019 – Demoralization is an existential distress syndrome that consists of an incapacity of coping, helplessness, hopelessness, loss of meaning and purpose, and impaired self-esteem. It can affect cancer patients, and the Demoralization Scale is a valid instrument to assess it. This study aimed to investigate the prevalence of demoralization in end-of-life (EoL) cancer patients and its associations with the medical and psychosocial variables. In addition, the latent dimensions of demoralization emerging in this distinctive population were explored. EoL cancer patients showed higher levels of demoralization than has been reported in other studies with advanced cancer. These data could suggest that demoralization could increase in proximity to death and with impaired clinical condition. In particular, the five demoralization dimensions that emerged could represent the typical concerns around which the syndrome evolves in EoL cancer patients. Finally, spiritual well-being could play a protective role with respect to demoralization. **Abstract (inc. list of references):** <http://bit.ly/2WM2Mzg>

## End-of-life care in England

### **Public responses to voluntary community care: Propositions for old age and end of life**

*PLOS ONE* | Online (In print) – Accessed 15 June 2019 – Funding shortages and an ageing population have increased pressures on state or insurance funded end-of-life (EoL) care for older people. Across the world, policy debate has arisen about the potential role volunteers can play, working alongside health and social care professionals in the community to support and care for the ageing and dying. A sample of 3,590 adults in England aged 45 or more from an online access panel responded to a questionnaire in late 2017. Preferences for different models of community volunteering were elicited. There was a preference for “formal” models with increased wariness of “informal” features. Whilst 32% of adults said they “might join” depending on whom the group helped, unsurprisingly more personal and demanding types of help significantly reduced the claimed willingness to help. Finally, willingness to help (or be helped) by local community carers or volunteers was regarded as less attractive than care being provided by personal family, close friends or indeed health and care professionals. Findings of this study suggest that if community volunteering to care for elderly people at the EoL in England is to expand it may require considerable attention to the model including training for volunteers and protections for patients and volunteers as well as public education and promotion. Currently, in England, there is a clear preference for non-medical care to be delivered by close family or social care professionals, with volunteer community care regarded only as a back-up option. Abstract: <http://bit.ly/2IOGSRR>

### **Radiation oncologists’ role in end-of-life care: A perspective from medical oncologists**

*PRACTICAL RADIATION ONCOLOGY* | Online – 12 June 2019 – Medical oncologists [i.e., study participants] expressed complex views regarding the role of radiation oncologists in end-of-life care (EoLC). Identified themes included the limited role of radiation oncologists, territorial concerns, capability, and desire of radiation oncologists in this realm, and the need for communication between providers. Radiation oncologists were compared with surgeons, whose interaction with patients ceased after their service had been performed. In this regard, control of palliative care referral or EoLC discussions was thought to be in the territory of medical oncologists who had longitudinal relationships with patients from diagnosis. Medical oncologists were concerned about the capability of radiation oncologists to accurately prognosticate, and stated radiation oncologists lacked knowledge of subsequent lines of systemic therapy available to patients. Radiation oncologists’ fear of upsetting medical oncologists was thought to be justified if they engaged in EoLC planning without direct permission from the referring medical oncologist. Radiation oncologists should focus on increasing open communication and teamwork with medical oncologists and demonstrate their ability to prognosticate and counsel patients regarding EoLC decisions. **Abstract (w. a link to references):** <http://bit.ly/2lh1tzs>

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

Representative sample of recent journal articles:

- *CANADIAN JOURNAL OF NURSING RESEARCH* | Online – 12 June 2019 – **‘Medically assisted dying in Canada: “Beautiful death” is transforming nurses’ experiences of suffering.** Nurses witness pain and distress up close and consequently experience their own suffering. A narrative study of Canadian nurses’ participating in medical assistance in dying (MAiD) found nurses’ previous witnessing of unresolved end-of-life (EoL) suffering has shaped their acceptance of medical assistance in dying. Little is known about the impact of participating in medically assisted dying on nurses’ suffering. An overarching narrative before the availability of MAiD is a culture of nurses’ taken-for-granted suffering: feeling terrible. After MAiD, two key narratives describe transformational feelings of a beautiful death and residual discomfort. Nurses found their suffering transformed when participating in MAiD; EoL care was satisfying and gratifying. And yet, unanswered questions due to worries of becoming desensitized and ongoing deeper questioning remain. Participating in MAiD has positively impacted nurses and starkly contrasts their previous experiences caring for those with unbearable suffering. **Abstract:** <http://bit.ly/2F9eWau>

## Publishing Matters

### **The association between quality measures of medical university press releases and their corresponding news stories. Important information missing**

*PLOS ONE* | Online – 12 June 2019 – This large study of medical university press releases and corresponding news stories showed that important measures of a scientific study such as funding and study limitations were omitted to a very large extent. The lay public and health personnel as well as policy makers, politicians and other decision makers may be misled by incomplete and partly inaccurate representations of scientific studies which could negatively affect important health-related behaviours and decisions. **Full text:** <http://bit.ly/2WEwPnl>

### **The war to free science: How librarians, pirates, and funders are liberating the world's academic research from paywalls**

U.S. | Vox Media – 10 June 2019 – The 27,500 scientists who work for the University of California (UC) generate 10% of all the academic research papers published in the U.S. Their university recently put them in a strange position: Sometime this year, these scientists will not be able to directly access much of the world's published research they're not involved in. That's because in February, the UC system – one of the country's largest academic institutions, encompassing Berkeley, Los Angeles, Davis, and several other campuses – dropped its nearly \$11 million annual subscription to Elsevier, the world's largest publisher of academic journals. On the face of it, this seemed like an odd move. Why cut off students and researchers from academic research? In fact, it was a principled stance that may herald a revolution in the way science is shared around the world. The university decided it doesn't want scientific knowledge locked behind paywalls, and thinks the cost of academic publishing has gotten out of control. Elsevier owns around 3,000 academic journals, and its articles account for some 18% of all the world's research output. This is a story about more than subscription fees. <http://bit.ly/2R1txcQ>

Noted in Media Watch 11 March 2019 (#605, p.16):

- CANADA | CBC ('Second Opinion') – 9 March 2019 – **'Breaking down the paywall that blocks access to the world's academic research.'** Canada's academic librarians are cheering from the sidelines now that the University of California has cancelled its subscriptions with the academic publishing giant Elsevier. It was a clash of titans as the largest public university in the U.S. pushed back against the multi-billion dollar paywall blocking open access to the world's scientific knowledge. Elsevier leads the "big five" group that also includes Springer Nature, Wiley, Taylor & Francis, and Sage. Altogether they publish more than 11,000 journals. Last year Canadian university libraries paid more than \$300 million for subscriptions to research journals including those containing papers generated by their own professors. **Full text:** <http://bit.ly/2C9DcYA>

### Media Watch: Editorial Practice

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