

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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To emerge on the right side of history, the entire culture of medicine needs to be turned around. End-of-life care is not just palliative care's business. It is everyone's business, from emergency room doctors to primary care physicians.

'The way we die will be considered unthinkable 50 years from now' (p.4), in Vox Media.

Canada

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The Globe & Mail* – 3 April 2019 – **'End-of-life commission sees "strong growth" in number of Quebecers seeking assisted death.'** The number of Quebecers seeking medical assistance in dying (MAiD) has been growing steadily since 2015, according to a report on the state of end-of-life care tabled in the provincial legislature. The commission created to oversee the Quebec law on assisted dying found that 1,632 people received MAiD between 10 December 2015, when the law came into effect, and 31 March 2018. Of those cases, 969 were in 2017-2018. This "strong growth" is much greater than what elected officials expected when the law was drafted, commission chairman Michel A. Bureau said. Almost all those who received MAiD had six months or less to live, 87% were at least 60 years old and 78% had cancer. Two-thirds of the deaths were in a hospital, while 20% were at the patient's home and 10% were in a long-term care centre. About one-third of the 2,462 total requests for MAiD were rejected, usually because the person did not meet the eligibility requirements. <https://tgam.ca/2CWniRz>

Specialist Publications

'Perceptions and intentions toward medical assistance in dying among Canadian medical students' (p.12), in *BMC Medical Ethics*.

'Information needs of francophone health care professionals and the public with regard to medical assistance in dying in Quebec: A qualitative study' (p.13), in *CMAJ Open*.

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<http://bit.ly/2ThijkC>

U.S.A.

Nursing facilities increasingly provide hospice care, report finds

MCKNIGHT'S LONG-TERM CARE NEWS (Northbrook, Illinois) | Online – 5 April 2019 – More nursing homes are providing hospice care, but such services remain largely underused, a new *LeadingAge* report finds.¹ The analysis notes that the hospices' prevalence has skyrocketed in recent years, with the number of providers nearly doubling since 2000, at about 4,200 in 2016. "Over the same period of time, the hospice patient population has changed drastically: hospice is now serving more individuals residing in nursing homes and assisted living in addition to its traditional home-based population," according to the report. In 2016, about half of all Medicare hospice beneficiaries died at home, while one-third died in a nursing home. Terminal conditions treated by the benefits have changed too. While the service was almost exclusively limited to cancer in the past, patients with dementia and heart disease are increasingly using it, too. Though hospice use has grown exponentially in recent years, utilization remains low, report authors note. About

28% of Medicare beneficiaries who used the benefit enrolled for fewer than seven days before death, and there is wide variation from state to state. About 18% of Medicare beneficiaries used hospice in Alaska at the low end, compared to 59% in Arizona. <http://bit.ly/2G48D9c>

Specialist Publications

'Compelling results that a problem-solving intervention improves hospice family caregiver outcomes' (p.8), in *Journal of the American Geriatric Society*.

'Use of advance care planning billing codes for hospitalized older adults at high risk of dying: A national observational study' (p.9), in *Journal of Hospital Medicine*.

'Update in hospice and palliative care' (p.9), in *Journal of Palliative Medicine*.

1. 'Non-profit hospice services report: Where mission and community meet,' *LeadingAge*, Washington DC, January 2019. **Download/view at:** <http://bit.ly/2lhCRfc>

Palliative care could cut health care costs by \$103 billion

FLORIDA | *Hospice News* (Chicago, Illinois) – 4 April 2019 – Palliative care (PC) could reduce societal health care costs by \$103 billion within the next 20 years, the non-profit economic research group Florida TaxWatch says in a report.¹ The group recommended that policymakers take action to expand PC utilization in the state. PC in general can reduce health care costs by more than \$4,000 per patient, according to a 2017 study.² It can also reduce the frequency of 911 calls, emergency department visits, and unnecessary hospitalizations. Many hospice providers offer PC in addition to their other services. Payors often treat it as a precursor to hospice, allowing patients to receive similar services until they become eligible for the hospice benefit. <http://bit.ly/2Vquv3A>

1. 'Palliative care in Florida: Challenges and options for Florida's future,' TaxWatch, March 2019. **Download/view at:** <http://bit.ly/2OT8liu>
2. 'A national strategy for palliative care,' *Health Affairs*, 2017;36(7):1265-1273 (noted in the 10 July 2017 issue of *Media Watch*, #520, pp.10). **Abstract:** <http://bit.ly/2UhfFzY>

When opposites attract, for life

THE NEW YORK TIMES | Online – 4 April 2019 – Of all the obstacles to initiating hospice that have been cited, from physician delays to inadequate resources, this one – the devotion of wife to husband, or child to parent, and their reluctance to welcome another into that bond – is the hardest to quantify. <https://nyti.ms/2Uxj8tv>

Older patients resist talking with doctors about their life expectancy, study finds

PENNSYLVANIA | *The Philadelphia Inquirer* – 4 April 2019 – Nancy Schoenborn, a geriatrician at Johns Hopkins University's School of Medicine, noticed that doctors increasingly are being told by their professional organizations to treat patients in the last decade or so of life differently. Less aggressive control of blood sugar and blood pressure makes sense for people with fewer years to go, the guidelines suggest. Screening tests for certain cancers probably won't be beneficial if a patient is unlikely to live at least an additional 10 years. The emphasis on life span rather than age stems from the recognition that health varies widely in the last chapters of life, and age alone is a poor predictor of how a patient is doing. A sick 65-year-old and a healthy 80-year-old might each have nine years left. These new rules, though, present doctors like Schoenborn with a problem. How exactly is she supposed to explain her treatment decisions to patients? This question led her to start asking older Americans how they want to talk about mortality with their doctors. Her recent survey ... revealed some surprising results.¹ <http://bit.ly/2UvxBpS>

1. 'Older adults' preferences for discussing long-term life expectancy: Results from a national survey,' *Annals of Family Medicine*, 2018;16(6):530-537 (noted in the 3 December 2018 issue of Media Watch, #592, p.11). **Full text:** <http://bit.ly/2Uhxyie>

Related

- REUTERS HEALTH | Online – 1 April 2019 – '**Doctors need to do better at talking to families about critically ill patients.**' Doctors' conversations with families about care for critically ill patients often fail to address patients' values and preferences, according to a study that suggests there's plenty of room for improvements in communication.¹ Researchers assessed what transpired in 244 conferences between clinicians and families of patients in acute respiratory distress and at least a 50% chance of dying in the hospital. Patients were 58-years-old on average and hospitalized in intensive care units. They were unable to advocate for themselves; families had to decide what treatment to provide, and when to focus on comfort care rather than aggressive interventions. Only 68% of these conferences included discussions of patients values and preferences for end-of-life care... <http://bit.ly/2FL8tC2>

1. 'Clinician-family communication about patients' values and preferences in intensive care units,' in *JAMA Internal Medicine*, published online 1 April 2019. **Key points/abstract:** <http://bit.ly/2UbAVqQ>

N.B. See also 'Clinician-family communication about patients' values and preferences in intensive care units,' *JAMA Internal Medicine*, published online 1 April 2019. **Abstract:** <http://bit.ly/2UbAVqQ>

Centers for Medicare & Medicaid Services to delay Hospice Compare data on "imminent death" quality measure

HOSPICE NEWS (Chicago, Illinois) | Online – 3 April 2019 – Citing a need for further testing, the U.S. Centers for Medicare & Medicaid Services (CMS) will not release Hospice Compare data on hospice visits during the last seven days of life as expected this summer. CMS uses Hospice Compare to publicly report hospice provider performance on quality measures. Referring organizations such as hospitals and nursing homes, as well as patients and families, are paying increasing attention to these scores when choosing a hospice. CMS requires hospice providers to submit data for two measures pertaining to the number of hospice visits a patient receives when death is imminent: 1) The percentage of patients who received one registered nurse (RN) or social worker visit during their last three days of life (three-day measure); and, 2) The percentage of patients that received two visits from an RN or social worker during the patient's final seven day (seven-day measure). CMS indicated that several months of comprehensive testing was needed to evaluate the seven-day measure's validity and reliability. The agency said that if testing were to result in substantial changes to the measure, it would submit a new rules for public comment. <http://bit.ly/2FNBe17>



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The way we die will be considered unthinkable 50 years from now

VOX MEDIA (Washington DC) | Online – 3 April 2019 – While the palliative care (PC) specialty has greatly improved end-of-life (EoL) care, too often, PC has been used as a way to avoid the culture change needed by all medical specialties to better handle death. Despite its many benefits, many patients and physicians are scared of “palliative care” because of its strong association with the EoL. Some have been compelled to change the title of their practices to “supportive care.” To many patients, the very name “palliative” implies that they will be abandoned, making them very reluctant to accept their services. The fact is that PC can, and should, be delivered to patients with serious illness alongside conventional care. But the issues go beyond the name – one recent study showed that PC-led meetings with families of patients in intensive care units led to an increase in post-traumatic stress disorder symptoms among family members.¹ PC specialists are often consulted in tense situations when patients are critically ill, and they often have no prior relationship with patients or their families, who might be unprepared to have serious discussions with them. That’s why most of these difficult conversations should be delivered by the doctors and surgeons primarily responsible for treating the patients. One study estimated that by 2030, the ratio between PC specialists and eligible patients will be 1 to 26,000.² PC specialists cannot be entirely responsible for EoL care by themselves. To emerge on the right side of history, the entire culture of medicine needs to be turned around. EoL care is not just PC’s business. It is everyone’s business, from emergency room doctors to primary care physicians. Physicians need to abandon outdated ideas that their role as healers is incompatible with helping patients die comfortably and on their own terms. Helping patients die well is as important as helping them live to the fullest. <http://bit.ly/2ul65qL>

1. ‘Effect of palliative care-led meetings for families of patients with chronic critical illness: A randomized clinical trial,’ *Journal of the American Medical Association*, 2016;316(1):51-62 (noted in 11 July 2016 issue of Media Watch, #470, p.15). **Full text (via PubMed):** <http://bit.ly/2VmZNby>
2. ‘Future of the palliative care workforce: Preview to an impending crisis,’ *American Journal of Medicine*, published online 29 September 2016 (noted in the 3 October 2016 issue of Media Watch, #482, p.6). **Full text:** <http://bit.ly/2K6VUGM>

N.B. Additional articles on the PC workforce in the U.S. noted in 3 October 2016 issue of Media Watch.

Congress tackles hospice and palliative care staffing shortage

HOSPICE NEWS (Chicago, Illinois) | Online 2 April 2019 – The ‘Palliative Care and Hospice Education and Training Act’ would provide funds to increase the number of permanent faculty in academic institutions that train hospice and palliative care (PC) providers, with the ultimate goal of growing the workforce. Other provisions would create a national campaign to promote the benefits of palliative and hospice care among healthcare providers and the public, and would expand National Institutes of Health research efforts on hospice care. Currently the U.S. has 13.35 hospice and PC specialists for every 100,000 adults 65 and older. A 2018 study estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000.¹ Hospice and PC providers are already seeing shortages in other disciplines, including chaplains, nurses, and social workers. As far back as 2008, the U.S. Centers for Medicare & Medicaid Service (CMS) began allowing hospice providers to use contracted nursing staff because not enough nurses were available to fill permanent positions. In 2015 only 44% of hospital PC programs met national staffing standards set by the Joint Commission. The shortages are exacerbated when considering the current rapid expansion of community-based PC, such as in outpatient and home-based settings. <http://bit.ly/2WljvyS>

1. ‘The growing demand for hospice and palliative medicine physicians: Will the supply keep up?’ *Journal of Pain & Symptom Management*, published online 2 February 2018 (noted in 16 July 2018 issue of Media Watch, #572, p.10). **Full text:** <http://bit.ly/2CRjxwO>

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Noted in Media Watch 16 July 2018 (#572, p.10):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2018;20(4):349-357. ‘**The hospice and palliative care advanced practice registered nurse workforce: Results of a national survey.**’ Advanced practice registered nurses are an important part of the interdisciplinary palliative care (PC) team, and strengthening this workforce can help alleviate the shortage of clinicians and improve access to quality PC. However, there is a dearth of information about this workforce. Sixty-three percent of respondents had more than 20 years of experience as a registered nurse yet were newer to practice as a hospice and PC advanced practice nurse, with 53.8% having 0 to 5 years of experience in this role. Forty-one percent indicated that their traditional graduate educational preparation was insufficient in preparing them for their specialty role. Most indicated that they did not experience barriers to practice in their current position, but 7.3% identified significant issues. **Abstract:** <http://bit.ly/2UncaHy>

Hospice units for soothing end-of-life care are themselves dying off

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 1 April 2019 – The National Hospice & Palliative Care Organization tracks use of hospice by the 1.4 million Americans who use that type of care in a given year, and it reports that only about 1% of their days of care are delivered in a dedicated, inpatient hospice facility. More than 55% is delivered at home, with most of the rest in a nursing home or similar long-term-care setting. Most of the home-like units closing were developed over the past 10 to 15 years as a peaceful alternative to nursing homes or hospitals for families for whom late-life care at home was too heavy a burden. To be admitted to such a unit, patients typically must have the most serious care needs, such as pain that cannot be sufficiently controlled at home. The operators are typically reimbursed by Medicare at a flat rate of about \$600 daily, more than three times as much as is typical for government reimbursement of home hospice care. It is also far more costly than nursing home care. So if the concept was in vogue a decade ago, with providers spending \$5 million or more to develop such facilities, looking ahead to large-scale growth in the elderly population of the region and U.S., what’s caused cutbacks? A few things, say hospice providers and analysts... <http://bit.ly/2uJFbOZ>

International

What is in the “best interests” of a patient where treatment is of no benefit?

U.K. (Scotland) | *The Scotsman* (Edinburgh) – 5 April 2019 – It is nearly 30 years since the Hillsborough disaster. One of the teenage survivors, Tony Bland, had an extraordinary impact on English law. He suffered a catastrophic brain injury and was left in a permanent vegetative state. This meant that, although awake, he had no awareness of himself, nor of his surroundings. He was able to breathe unaided and his heart was strong. As he could not feed himself or swallow, he was fed via a tube. After four years in this tragic situation, the hospital and his family approached the English courts to stop tube feeding. This was granted because it was considered to be not in his best interests. The court found that the principle of the sanctity of life was not absolute in its eyes. It was not violated by stopping medical treatment to which he had not consented. Treatment gave, in the court’s perspective, no benefit. However, it recommended that such cases should continue to

be brought to court. This was not the situation in Scotland where judicial review was not required. However, in 2018, the U.K. Supreme Court ruled that court review is no longer required in - England either if the family and medical team agree to stop feeding. This also applied to patients in minimally conscious states. <http://bit.ly/2uL5BQH>

Specialist Publications

‘What do we owe the newly dead? An ethical analysis of findings from Japan’s corpse hotels workers’ (p.6), in *Bioethics*.

‘Informed consent and advance care directives: Cornerstones and outstanding issues in the newly enacted Italian legislation’ (p.10), in *The Linacre Quarterly*.

Cont.

Noted in Media Watch 6 august 2018 (#575, pp.6-7):

- U.K. (England, Northern Ireland, Scotland & Wales) | BBC News (London) – 30 July 2018 – ‘**Supreme Court backs agreed end-of-life decisions.**’ Legal permission will no longer be required to end care for patients in a long-term permanent vegetative state, the Supreme Court has ruled.¹ It will now be easier to withdraw food and liquid to allow such patients to die. When families and doctors are in agreement, medical staff will be able to remove feeding tubes without applying to the Court of Protection. [Justice] Lady Black ruled there was no violation under the Human Rights Convention. The Court of Protection has ruled on cases for 25 years, but the process can take months or years, and it costs health authorities about £50,000 in legal fees to lodge an appeal. The ruling could have an impact on the thousands of families whose loved ones are in a vegetative state. It is estimated about 24,000 people in the U.K. are in a persistent vegetative state or a minimally conscious state. <https://goo.gl/9hJEzs>

1. ‘An NHS Trust and others (Respondents) v Y (by his litigation friend, the Official Solicitor) and another (Appellant),’ The Supreme Court, 30 July 2018. **Download/view at:** <https://goo.gl/97i4Ve>

Army throws open Eastern India’s first palliative care centre

INDIA (West Bengal) | Newsmen (Kolkata) – 4 April 2019 – The Army, with the assistance from corporate houses, has thrown open a palliative care centre at Barrackpore Cantonment in North 24-Parganas for the terminally ill armed forces personnel. The 15-bed facility is the first of its kind in the Eastern Command jurisdiction that covers eastern and northeast India. It has been named SPARSH. The centre aims to provide succour to terminally ill armed forces personnel who are beyond active medical treatment and are suffering from diverse ailments such as cancer, neurological disorders, and other critical maladies. The centre is focused on medical comfort, intensive care unit, psychological and physiological therapy combined with yoga in an aesthetically pleasing environment. <http://bit.ly/2ORg1az>

N.B. Sparsh is the Sanskrit word for touch.

Doctors not liable for artificially delaying death, rules German court

GERMANY | *Deutsche Welle* (Bonn) – 2 April 2019 – A doctor is not financially liable for prolonging their patients lives by using feeding tubes, ventilators or other artificial means, Germany’s Federal Court of Justice has ruled. The high court ruling was being watched anxiously by doctors, as it could have had serious legal implications for medical practitioners providing end-of-life care to seniors and patients in vegetative states. What the court decided: 1) Prolonging someone’s life cannot be viewed as damaging or harmful, the court ruled; 2) Doctors do not have to pay damages for pain and suffering for keeping someone alive, even if there are few prospects of recovery; 3) The case involved a man who sued a doctor for €40,000 (USD \$44,800) in damages for keeping his father alive for five years with a feeding tube; and, 4) The court overturned a ruling by a lower court that initially ruled in the son’s favor. <http://bit.ly/2YJhnsr>

Specialist Publications

What do we owe the newly dead? An ethical analysis of findings from Japan’s corpse hotels workers

BIOETHICS | Online – 4 April 2019 – While people are still alive, we owe them respect. Yet what, if anything, do we owe the newly dead? This question is an urgent practical concern for aged societies, because older people die at higher rates than any other age group. One novel way in which Japan, the frontrunner of aged societies, meets its need to accommodate high numbers of newly dead is *itai hoteru* or corpse hotels. *Itai hoteru* offer families a way to wait for space in over-crowded crematoriums while affording an environment conducive to grieving. Drawing on conversations with *itai hoteru* employees, the authors delineate the values this contemporary death practice expresses and show how these values comprise part of the broader idea of a good death. A good death implies duties on both sides of death’s divide: to both the dying and the newly dead. **Abstract:** <http://bit.ly/2TUx10F>

Factors influencing palliative care in advanced dementia: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 3 April 2019 – Thirty-four studies were included. Twenty-five providing qualitative data, 6 providing quantitative data and 3 mixed methods studies. The findings identified organisational, healthcare professionals and patients-related barriers and facilitators in provision of palliative care (PC) for people with advanced dementia from perspective of stakeholders across different care settings. The most commonly reported barriers are lack of skills and training opportunities of the staff specific to PC in dementia, lack of awareness that dementia is a terminal illness and a palliative condition, pain and symptoms assessment/management difficulties, discontinuity of care for patients with dementia and lack of coordination across care settings, difficulty communicating with the patient and the lack of advance care planning. Even though the provision of PC was empirically recognised as a care step in the management of dementia, there are barriers that hinder access

of patients with dementia to appropriate facilities. With dementia prevalence rising and no cure on the horizon, it is crucial that health and social care regulatory bodies integrate a palliative approach into their care using the identified facilitators to achieve optimal and effective PC in this population. **Abstract:** <http://bit.ly/2uU7JWt>

Publishing Matters

‘The importance of pre-defined rules and pre-specified statistical analyses: Do not abandon significance’ (p.13), in *Journal of the American Medical Association*.

‘Plagiarism in predatory publications: A comparative study of three nursing journals’ (p.14), in *Journal of Nursing Scholarship*.

“‘Predatory’ scientific publisher is hit with a \$50 million judgment’ (p.14), in *The New York Times*.

Noted in Media Watch 1 April 2019 (#608, p.10):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 25 March 2019 – **‘Dying with dementia: Under-recognized and stigmatized.’** Alzheimer’s disease, the most common dementia etiology, is the sixth leading cause of death in the U.S. and is one of the few leading causes of death where the age-adjusted death rate is increasing. Even more people die with dementia as a co-morbidity to another serious illness or illnesses, although dementia is not officially the cause of death. In total, 30% of all decedents older than 65 years in the U.S. die with or from dementia. The number of individuals with dementia enrolled in hospice has increased exponentially over the past 20 years, to the point that almost half of all hospice recipients annually have a primary or comorbid diagnosis of dementia. **Full text:** <http://bit.ly/2HGT0q4>

N.B. Additional articles on PC for people living with Alzheimer’s and other forms of dementia noted in this issue of Media Watch.

End-of-life care in Canada

Impact of comprehensive hospice palliative care on end-of-life care: A propensity-score-matched retrospective observational study

CMAJ OPEN | Online – 4 April 2019 – This study provides three key findings: 1) Enrolment in the Symptom Management Program was associated with lower rates of measures of potentially aggressive end-of-life care (EoLC) for residents in Greater Sudbury & District (Ontario, Canada); 2) Provision of hospice palliative care (HPC) was associated with lower rates of death in the acute care hospital setting; and, 3) Family caregiver satisfaction with advanced cancer care received through the program, assessed as an overall total satisfaction score or through individual scales, appeared high, although scores were similar to those in other studies assessing caregiver satisfaction with provision of palliative oncology services. The results suggest that provision of HPC may be associated with avoidance of high resource costs related to aggressive EoLC or death in an acute care hospital. **Full text:** <http://bit.ly/2YMoOKJ>

Multidimensional emotion regulation strategies among hospice nurses

DEATH STUDIES | Online – 2 April 2019 – The purpose of this study was to investigate relationships between four emotion regulation strategies (intrinsic affect-improving, intrinsic affect-worsening, extrinsic affect-improving, and extrinsic affect-worsening) and compassion fatigue, job satisfaction, and life satisfaction among 90 hospice nurses who completed an online survey. Intrinsic affect-improving was associated with higher life satisfaction. Intrinsic affect-worsening was associated with higher compassion fatigue and lower life satisfaction. Extrinsic affect-worsening was associated with lower job satisfaction. Overall, these findings support a multidimensional approach to understanding emotion regulation among hospice nurses. **Abstract:** <http://bit.ly/2WMn9rk>

End-of-life care in Belgium

Integrated palliative care for nursing home residents: Exploring the challenges in the collaboration between nursing homes, home care and hospitals

INTERNATIONAL JOURNAL OF INTEGRATED CARE | Online – 3 April 2019 – In several countries and health domains, governments aim to integrate the provision of care by creating care networks. Based on this case study, the following policy recommendations can be made. First of all, the implementation of a care network does not guarantee successful collaboration between care organisations. In this mixed-method study, the coordinators of palliative care (PC) networks identify the need to formalise the interaction between various healthcare organisations with regard to PC, the establishment of formal channels of communication and information exchange, as well as the development of shared leadership. Secondly, when designing care networks, leadership positions should be taken into consideration. Given the difficulties network coordinators encounter with shared leadership, interpersonal skills training could be of benefit to their professional development. Also, incentives could be put forward to motivate key persons to attend meetings. Research needs to contribute more to the current understanding of how leadership is “made to happen.” Future studies could validate the results by exploring the views of “key persons” on inter-organisational collaboration in networks, leading to a more comprehensive understanding of the challenges in collaboration. **Full text:** <http://bit.ly/2HXajU7>

Compelling results that a problem-solving intervention improves hospice family caregiver outcomes

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 4 April 2019 – Nearly 1.4 million patients receive hospice services annually in the U.S. Many of these patients are cared for at home with the support of uncompensated family caregivers (FCGs), such as a spouse or an adult child. The hospice model of care relies heavily on FCGs to ensure that community-dwelling patients are getting the high-quality care they need. This is critically important because, when asked about end-of-life (EoL) care preferences, most individuals express a desire to remain at home and with family during their dying days. Although the caregiving experience can be rewarding for family members, it is frequently burdensome as well. Hospice FCGs frequently report feeling unprepared and anxious about their role – and that caregiving tasks can be physically and emotionally taxing. Some evidence suggests that caregiving-related burden may be detrimental to one’s health. To improve care for patients at the EoL, scholars, clinicians, and policymakers must do a much better job of supporting natural support networks and informal caregivers. Unfortunately, hospice FCGs are an understudied population. Hospice researchers Demiris, Parker Oliver, Washington, and Pike should be commended for their recent successful clinical trial evaluating the Problem-Solving Intervention to Support Caregivers in End-of-Life Care Settings (PISCES) intervention.¹

Editorial (full text): <http://bit.ly/2YOIjbq>

1. ‘A problem-solving intervention for hospice family caregivers: A randomized clinical trial,’ *Journal of the American Geriatric society*, published online 4 April 2019. **Abstract:** <http://bit.ly/2G3uVru>

Use of advance care planning billing codes for hospitalized older adults at high risk of dying: A national observational study [in the U.S.]

JOURNAL OF HOSPITAL MEDICINE, 2019; 14(4):229-231. As the U.S. population ages, hospitals and health systems around the country have been grappling with how to integrate advance care planning (ACP) into routine practice. In 2016, the Centers for Medicare & Medicaid Services began paying physicians for ACP by introducing two new billing codes which allowed them to bill for up to 60 minutes of advance care planning (ACP) conversations with their patients. At the time, some lawmakers expressed concern that the ACP billing codes could be overused and become a burden to the Medicare program. A team of researchers from the Dartmouth Institute for Health Policy & Clinical Practice investigated the early uptake of the ACP billing codes by analyzing billing for seriously ill, hospitalized adults over 65 who were treated by a large national physician practice. They found that despite the fact that physicians employed by the practice received ACP training and small financial incentives for ACP documentation, the rate of billed

ACP conversations was very low and that there was wide variation among physicians and practice sites. **Abstract:** <http://bit.ly/2JX27oC>



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog – Posted 3 April 2019 – ‘**Advance Care Planning and advance directives: A clear and concise expression of the patient’s wishes regarding personal care and medical treatment or therapeutic interventions.**’ <http://bit.ly/2WGfon1>

Improving quality of palliative care through implementation of National Guidelines for Palliative Care [in Singapore]

JOURNAL OF PALLIATIVE MEDICINE | Online – 2 April 2019 – This article describes the development and implementation of National Guidelines for Palliative Care (NGPC) in Singapore. The NGPC was developed through literature review, multidisciplinary inputs, and modified RAND Delphi method. Quality measures for the guidelines were developed through literature review and multidisciplinary inputs and implemented with an audit of specialist palliative care (PC) providers. The NGPC consisted of 13 guidelines and 64 quality measures. A total of 11 PC services (73.3%) participated in the audit from September 2015 to October 2015. National-level and service-level gaps in quality of care were identified and individual providers identified priority areas for improvement. The authors successfully developed the national PC guidelines and quality measures. They implemented voluntary self-assessment among healthcare institutions in various settings nationally that serve to catalyze quality improvement and cultivate a culture of quality improvement. **Abstract:** <http://bit.ly/2lc4FfZ>

Update in hospice and palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 27 March 2019 – The objective of this update, presented at the 2018 Annual Assembly of the American Association of Hospice & Palliative Medicine (AAHPM) and the Hospice & Palliative Nurses Association (HPNA), is to identify, summarize, and critique a sampling of recent research that has the potential for marked impact on hospice and palliative clinical practice. In a departure from previous years, the authors surveyed AAHPM and HPNA members to determine focused topic areas, from which they selected candidate articles. The two topic areas selected by the membership were “Moving into the great beyond: bringing palliative care (PC) into the subspecialties” and “Improving the conversation for patients with



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serious illness.” Seven reports of original research published between 1 January 2012 and 3 November 2017 were identified through a systematic search of relevant databases, hand searching of leading journals, and discussion with experts in the field. Candidate articles were scored and ranked independently by four reviewers based on methodological quality, appeal to a breadth of PC clinicians across settings, and potential for impact. The authors summarize the seven articles with the highest ratings. **Abstract:** <http://bit.ly/2Vil2LX>

Oncology nurse managers’ perceptions of palliative care and end-of-life communication

JOURNAL OF PEDIATRIC ONCOLOGY NURSING | Online – 3 April 2019 – This study ... was part of a larger, multi-site study aimed at understanding pediatric oncology nurses’ experiences of palliative care/end-of-life (PC/EoL) communication. Nurses were assigned to focus groups based on length or type of experience... Eleven nurse managers (NMs) from three Midwestern pediatric hospitals [in the U.S.] with large oncology programs participated in one focus group. Findings include NMs’ overall experience of “fostering a caring climate,” which includes three core themes: 1) Imprint of initial grief experiences and emotions; 2) Constant vigilance: Assessing and optimizing family-centered care; and, 3) Promoting a competent, thoughtful, and caring workforce. Findings indicate that pediatric oncology NMs draw on their own PC/EoL experiences and their nursing management knowledge to address the PC/EoL care learning needs of nursing staff and patient/family needs. NMs need additional resources to support nursing staff’s PC/EoL communication training, including specific training in undergraduate and graduate nursing programs and national and hospital-based training programs. **Abstract:** <http://bit.ly/2OOEzAV>

Healthcare needs of older women prisoners: Perspectives of the healthcare workers who care for them

JOURNAL OF WOMEN & AGING | Online – 4 April 2019 – The proportion of older incarcerated women is growing, yet little is known regarding their healthcare needs. This study sought to elucidate the unique health-care needs of older women prisoners through the perspectives of correctional healthcare providers. Three organizing themes emerged regarding the health of older women prisoners: 1) The meaning of being “older” in the prison setting; 2) Challenges impacting correctional healthcare workers’ care delivery; and, 3) Unmet healthcare-related needs. Correctional healthcare workers’ insights can provide guidance regarding how to optimize the health of the increasing population of older women prisoners. **Abstract:** <http://bit.ly/2uNwbsf>

N.B. A compilation of selected articles, reports, etc., on end-of-life care in the prison system noted in past issues of the weekly report is posted on the Palliative Care Network website. **Download/view at:** <http://bit.ly/2RdegnL>

Informed consent and advance care directives: Cornerstones and outstanding issues in the newly enacted Italian legislation

THE LINACRE QUARTERLY | Online – 29 March 2019 – The Italian parliament has for the first time regulated the issue of consent and refusal of healthcare treatments, whether currently expressed or expressed in advance. This article elaborates on recent Italian legislation that details a patient’s right to consent to or refuse treatment in advance, including refusal of artificial nutrition and hydration, the duty of doctors in the event of an emergency, the shared planning treatment, the role of durable power of attorney, and advance healthcare directives. **Abstract:** <http://bit.ly/2I29F6L>

N.B. Additional articles on the Italian legislation on informed consent and advance directives noted in 11 March 2019 issue of Media Watch (#605, p.7).



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

The myth of “no place like home” when it comes to end of life

MEDICAL PRESS | Online – 3 April 2019 – In a new study, Jacquelyn Benson, assistant professor of human development and family science at the University of Missouri, found that home deaths can be physically and emotionally challenging, especially for caregivers.¹ “The realities of a home death experience present challenges for family members, especially those with limited resources and social support,” Benson said. “It is important that people understand that home death does not automatically equate a good death.” In recent decades, there has been a groundswell of social movements championing the ideal of dying at home. According to the Centers for Disease Control & Prevention, home deaths in the U.S. increased nearly 30% from 2000 to 2014, while deaths in hospitals, nursing homes and long-term care communities dropped. Researchers uncovered several themes that exposed the challenges that are often not included in conversations about dying at home. In some cases, challenges arose because there was uncertainty for the decision maker, and some caregivers were not prepared for making decisions regarding the end of a loved one’s life. The researchers also found that financial resources and strong relationships can help in differentiating good deaths from bad ones. Researchers found that the “good” death experiences involved high levels of emotional support for the dying individuals and the caregivers, and that the place of death played less of a role. **Full text:** <http://bit.ly/2FQn2UW>

1. ‘The motivations and consequences of dying at home: Family caregiver perspectives,’ *Journal of Housing For the Elderly*, 2018;32(3-4):278-336 (noted in the 5 November 2018 issue of Media Watch, #588, p.8). **Abstract:** <http://bit.ly/2UrFwVh>

Noted in Media Watch 12 October 2015 (#431, p.9):

- *BRITISH MEDICAL JOURNAL* | Online – 7 October 2015 – ‘**Is home always the best and preferred place of death?**’ Focusing on place of death as the key indicator of quality in end-of-life care distracts attention from the experience of dying for patients and their families. Evidence suggests that place of death is not the overriding priority. Control of symptoms, especially pain, and being accompanied by loved ones are more important. Much greater understanding of patient and public experience and attitudes to death and dying is needed, including where this should occur. When patients wish to die at home, every effort should be made to achieve this outcome. However, until resources are in place to adequately and equitably support home deaths, the current promotion of patient choice risks raising expectations that are not realised. There are also many reasons why patients may not wish to die at home. **Abstract:** <http://bit.ly/2CVNwUw>

Palliative care services in families of males with muscular dystrophy: Data from Muscular Dystrophy Surveillance & Research Network

SAGE OPEN MEDICINE | Online – 27 March 2019 – This study presents data from a population-based sample of [233] young men with Duchenne and Becker muscular dystrophy (DBMD) and their families regarding their use of palliative care (PC) services. The data support the following conclusions: 1) Although overall use of PC is high among families of males with DBMD, use of individual PC services is extremely variable; 2) All but one of the individual PC services were used by less than 50% of families and 9 of the 14 services were used by 37% or less families; and, 3) Use of PC services is associated with fewer predisposing and enabling characteristics such as primary caregiver’s education and family income than it is with the needs of affected males. PC services improve the quality of life (QoL) for both caregiver and individuals with progressive conditions like DBMD. The authors’ data suggest these services are underutilized among families of individuals with DBMD. Furthermore, their study points to a continuing need to educate healthcare providers and the public about PC and its capabilities for improving the QoL among individuals with conditions like DBMD and their families. Redefining the role of PC for life-limiting pediatric conditions and incorporating these services early on in the disease process within specialty clinics would be an important next step in the process and would improve the understanding and awareness of available services. It would also foster proactive decision-making for families who are taught to deal with their child’s disease progression as living with a progressive disease rather than reaching various phases of decline toward death. **Full text:** <http://bit.ly/2FIEpXP>

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N.B. In addition to the 249 patients, 451 surrogates and 144 clinicians at 13 ICUs at 6 U.S. academic and community medical centers were included in this study. Additional articles on PC for patients living with a neuromuscular disease noted in 18 September 2017 issue of Media Watch (#530, p.11).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- **ANAESTHESIA** | Online – 14 March 2019 – **‘A right to be unconscious.’** Sinmyee *et al* identify that common protocols for assisted dying ... fail to guarantee unconsciousness before death, and so admit the possibility of significant suffering through awareness during the dying process.¹ They argue “recent lessons from anaesthesia lead us to conclude that if we wish better to ensure unconsciousness at the point of death, then this can be achieved using: 1) Continuous drug infusions at very high concentrations; 2) Concomitant EEG-based brain function monitoring, targeted to the very low, burst suppression or isoelectric values; and, 3) Clinical confirmation of unconsciousness ... Alternative methods that do not include these elements entail a higher, possibly unacceptable, risk of remaining conscious and so, by definition, are suboptimal.” This seems to be an important, landmark paper ... because the issues it addresses are important in their own right: how to ensure death without suffering in jurisdictions where assisted dying (including assisted suicide or euthanasia) is allowed... Moreover, the paper shows the potential for the use of anaesthesia in contexts beyond surgery. **Full text:** <http://bit.ly/2FO9quF>
 1. ‘Legal and ethical implications of defining an optimum means of achieving unconsciousness in assisted dying,’ *Anaesthesia*, published online 20 February 2019 (noted in 25 February 2019 issue of Media Watch, #603, p.5). **Full text:** <http://bit.ly/2XcOfJz>
- **BMC MEDICAL ETHICS** | Online – 2 April 2019 – **‘Perceptions and intentions toward medical assistance in dying among Canadian medical students.’** Amid much public debate, medical assistance in dying (MAiD) was legalized in Canada in 2016. However, there remains a dearth of national-level empirical evidence on the opinions and intentions of doctors and medical students about their willingness to provide this new type of practice. As the next cohort of Canadian physicians prepares to enter medical practice under a changing legal landscape, more research is needed to investigate whether Bill C-14 adequately responds to the needs and concerns of patients and physicians in the clinical setting. The authors provide a systematic measurement of Canadian medical student opinion by surveying students at 15 of Canada’s 17 medical schools. Medical students from Québec and those who report being non-religious were significantly more willing to participate in MAiD. Medical students who identify as Christian, and medical students of any religion who attend religious services more frequently than once per month, were significantly less likely to participate in MAiD. Type of religion and frequency of religious attendance emerged as dominant variables, overshadowing the effect of province of birth, or of being born outside Canada. The authors’ findings provide the first national-level data of medical student opinion on the legalization of MAiD since this monumental change in Canada’s medical and legal landscape, and will inform the ongoing public debate around this emerging medical practice. **Full text:** <http://bit.ly/2TVLfv9>
- **BRITISH MEDICAL JOURNAL** | Online – 2 April 2019 – **‘We risk our careers if we discuss assisted dying, say U.K. palliative care consultants.’** Five anonymous palliative care doctors say that, although views diverge among specialists, palliative medicine’s professional association is stifling free speech on assisted dying. Between them they have 94 years of consultant level experience in palliative

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[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>

medicine. They share concerns about the way that their specialty's medical colleges represent assisted dying in the media, including in this journal. The Royal College of Physicians (RCP), after a recent survey of its members and fellows, adopted a neutral position on assisted dying. Since the survey was announced, there has been an outpouring of strong opinions in the media from the officers and members of the Association for Palliative Medicine (APM).¹² Most criticised the RCP for not following the APM's absolute opposition to a change in U.K. law to allow some forms of assisted dying. Fortunately, This journal has restored some balance by publishing articles from Canadian physicians who have experience of providing assisted dying. **Introductory paragraphs:** <http://bit.ly/2VkBjQt>

- *CMAJ OPEN* | Online – 4 April 2009 – ‘**Information needs of francophone health care professionals and the public with regard to medical assistance in dying in Quebec: A qualitative study.**’ The findings of this study show that health care professionals and members of the public have common information needs regarding medical assistance in dying (MAiD) and seek information on the relational, emotional and symbolic aspects of this practice. These findings call for concerted efforts to build a common information base – covering dimensions that go beyond the medical and legal aspects of MAiD – to facilitate informed conversations among patients, health care professionals and members of the public. **Full text:** <http://bit.ly/2W08Qm6>
- *SOCIOLOGY OF HEALTH & ILLNESS* | Online – 4 April 2019 – ‘**Expanded definitions of the “good death”? Race, ethnicity and medical aid in dying.**’ The range of end-of-life (EoL) options is expanding across North America. Specifically, medical aid in dying (AiD), or the process by which a patient with a terminal illness may request medical assistance with hastening death, has recently become legal in eight jurisdictions in the U.S. and all of Canada. Debates about AiD often rely on cultural constructions that define some deaths as “good” and others as “bad.” While research has found commonalities in how patients, family members and health care providers define good and bad deaths, these constructions likely vary across social groups. Because of this, the extent to which AiD is seen as a route to the good death also likely varies across social groups. The authors analyse qualitative data from six focus groups across three racial and ethnic groups: African American, Latino and white Californians, just after a medical AiD law was passed. They find that definitions of the “good death” are nuanced within and between groups, suggesting that different groups evaluate medical AiD in part through complex ideas about dying. These findings further conversations about racial and ethnic differences in choices about EoL options. **Abstract:** <http://bit.ly/2UhmXUI>

Publishing Matters

The importance of pre-defined rules and pre-specified statistical analyses: Do not abandon significance

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 4 April 2019 – For decades, statisticians and clinicians have debated the meaning of statistical and clinical significance. In general, most journals remain married to the frequentist approach to statistical testing and using the term statistical significance. A recent proposal to ban statistical significance gained campaign-level momentum in a commentary with 854 recruited signatories.¹ The petition proposes retaining P values but abandoning dichotomous statements (significant/non-significant), suggests discussing “compatible” effect sizes, denounces “proofs of the null,” and points out that “crucial effects” are dismissed on discovery or refuted on replication because of non-significance. The proposal also indicates that “we should never conclude there is ‘no difference’ or ‘no association’ just because a P value is larger than a threshold such as 0.05 or, equivalently, because a confidence interval includes zero,”¹ and that categorization based on other statistical measures ... should be discouraged. Other recent articles have also addressed similar topics, with an entire supplemental issue of a statistics journal devoted to issues related to P values. Changing the approach to defining statistical and clinical significance has some merits; for example, embracing uncertainty, avoiding hyped claims with weak statistical support, and recognizing that “statistical significance” is often poorly understood. However, technical matters of abandoning statistical methods may require further thought and debate. **Full text:** <http://bit.ly/2G2JKL1>

1. ‘Scientists rise up against statistical significance,’ *Nature*, published online 20 March 2019 (noted in the 25 March 2019 issue of *Media Watch*, #607, p.17). **Full text:** <https://go.nature.com/2TkvPU0>

Plagiarism in predatory publications: A comparative study of three nursing journals

JOURNAL OF NURSING SCHOLARSHIP | Online – 5 April 2019 – A serendipitous finding of several instances of plagiarism via duplicate publications during the random analysis of articles in a study examining the quality of articles published in predatory journals prompted this investigation. The extent and direction of duplication from one given journal to another was established. Changes made in subsequent publications, as a potential distraction to identify plagiarism, were also identified. There were 100 (68%) exact and near exact matches in the paired articles. The time lapse between the original and duplicate publication ranged from 0 to 63 months, with a mean of 27.2 months. Authors were from 26 countries, including Africa, the U.S., Turkey, and Iran. Articles with similarity scores in the range of 20% to 70% included possible similarities in content or research plagiarism, but not to the extent of the exact or near exact matches. The majority of the articles went from Journal A or C to Journal B, although four articles were first published in Journal B and then Journal A. This study found a substantial level of plagiarism via duplicate publications in the three analyzed predatory journals, further diluting credible scientific literature and risking the ability to synthesize evidence accurately to inform practice. Editors should continue to use electronic plagiarism detection tools. Education about publishing misconduct for editors and authors is a high priority. Abstract: <http://bit.ly/2CXya1G>

“Predatory” scientific publisher is hit with a \$50 million judgment

THE NEW YORK TIMES | Online – 3 April 2019 – In the world of scientific research, they are pernicious impostors. So-called predatory journals, online publications with official-sounding names, publish virtually anything, even gibberish, that an academic researcher submits – for a fee. Critics have long maintained that these journals are eroding scientific credibility and wasting grant money. But academics must publish research to further their careers, and the number of questionable outlets has exploded. Now the Federal Trade Commission (FTC) has stepped in, announcing ... that it has won a \$50 million court judgment against Omics International of Hyderabad, India... Omics publishes hundreds of journals in such areas as medicine, chemistry and engineering. It also organizes conferences. The TC. claimed that Omics violated the agency’s prohibition on deceptive business practices. In addition to the judgment, a federal judge in Nevada – where Omics has mail drops – ordered the company to cease its deceptive business practices, including failing to disclose fees, misleading authors about the legitimacy of its journals and marketing conferences with star speakers who never agreed to participate. <https://nyti.ms/2VsyWex>

N.B. OMICS publications include the *Journal of Palliative Care & Medicine*: <http://bit.ly/2TVQkXv>

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.

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Media Watch: Behind the Scenes

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