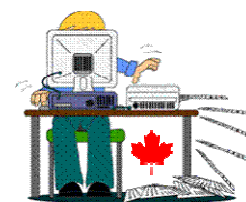


## Media Watch...

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

**Despite the high prevalence of dementia at the end-of-life, discussions about dementia rarely acknowledge its terminal nature. In the ... U.S. 'National Plan to Address Alzheimer's Disease: 2018 Update,' the term "death" appears just twice, "hospice" once, and "palliative care" four times.**

**'Dying with dementia: Under-recognized and stigmatized' (p.10), in *Journal of the American Geriatric Society*.**

## Canada

### Toronto doctors sued for allegedly ignoring veteran's wishes to stay alive

ONTARIO | CTV News (Toronto) – 24 March 2019 – A civil trial is set to begin this week for two doctors accused of ignoring an elderly man's wishes to stay alive and allegedly imposing a "do not resuscitate" order without consulting him or his substitute decision-maker. The \$2.2-million suit ... accuses the physicians of negligence or malpractice in the death of World War II veteran Douglas DeGuerre. The suit, filed by DeGuerre's daughter Joy Wawrzyniak, alleges the doctors overruled the family's decision to keep seeking treatment for DeGuerre's many serious illnesses. It alleges the doctors changed DeGuerre's status from "full code" – meaning make all reasonable efforts to keep the patient alive – to "do not resuscitate," without asking DeGuerre or consulting Wawrzyniak, who was tasked with making decisions on his behalf. Wawrzyniak had twice filed complaints to the College of Physicians & Surgeons of Ontario, neither of which resulted in any action being taken. In 2014, however, the province's Health Professions Appeal & Review Board ruled that the college failed to consider the key question in the case. "The question before the committee was whether it was within the standard of practice of the profession for such order to be made without consent from (Wawrzyniak)," the board wrote. "In other words, who makes decisions relating to the patient's plan of treatment?" According to board documents, the college changed its position in 2015, finding that while the doctors had exercised sound clinical judgment, they failed in their duty to tell Wawrzyniak about her father's change in code status. The college opted not to take disciplinary measures, but updated its own end-of-life policy. <http://bit.ly/2UUSRII>

**N.B.** 'Planning for and Providing Quality End-of-Life Care' (updated May 2016), College of Physicians & Surgeons of Ontario. **Download/view at:** <http://bit.ly/2CCjgoR>

Cont. next page



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Noted in Media Watch 22 June 2015 (#415, p.1):

- ONTARIO | *The Toronto Star* – 17 June 2015 – ‘**Watchdog cautions doctors in Sunnybrook end-of-life case.**’ After twice exonerating two Sunnybrook [Health Sciences Centre] doctors for their conduct in a controversial 2008 end-of-life case, Ontario’s medical watchdog has had what experts are calling an unprecedented change of heart. The College of Physicians & Surgeons has issued written cautions against Drs. Martin Chapman and Donald Livingstone after previously rejecting a formal complaint and two appeals by the daughter of a man they treated. <http://bit.ly/2TpsK4Y>

## U.S.A.

### **Kentucky passes law to expand palliative care**

KENTUCKY | *Hospice News* (Chicago, Illinois) – 27 March 2019 – Kentucky Governor Matt Bevin signed into law legislation to expand awareness and utilization of palliative care (PC) throughout the state. Bill 65 will establish a Palliative Care Interdisciplinary Advisory Council as well as a Professional Information & Education Program by July 2020. Hospice and PC providers nationwide have long worked to increase public awareness and understanding of their services. Misconceptions about these types of care have been a significant barrier to greater utilization. The Centers to Advance Palliative Care estimates that 70% of people in the U.S. are “not at all knowledgeable” about PC. A March 2018

study<sup>1</sup> ...found that community-dwelling adults had a low level of awareness of hospice and PC and that misinformation was common, concluding that education initiatives were needed to raise awareness and reduce misconceptions about these services. <http://bit.ly/2UinKnb>

#### **Specialist Publications**

‘**Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey**’ (p.12), in *Journal of Pain & Symptom Management*.

1. ‘Awareness and misperceptions of hospice and palliative care: A population-based survey study,’ *American Journal of Hospice & Palliative Medicine*, published online 20 June 2017 (noted in 26 June 2017 issue of Media Watch, #518, p.6). **Full text (via PubMed):** <http://bit.ly/2U2dXCI>

### **Envisioning better end-of-life care**

NEW JERSEY | NJ Spotlight (Newark) – 27 March 2019 – New Jerseyans nearing the end of life (EoL) undergo more aggressive medical treatments than patients in any other state, studies show, and in facilities where care costs an average twenty percent more than elsewhere.<sup>1</sup> Only three in 10 state residents pass away in the comfort of their own home, despite the wishes of many to avoid dying in a healthcare facility; that’s partly because few have clearly documented how they want to spend their final days or shared that information with family. The gap between patient goals for EoL care and actual outcomes is the focus of growing attention nationwide – and in New Jersey whose senior population is 1.35 million. While state and

healthcare providers are working to build a coordinated system to document people’s EoL desires, progress has been slow, complicated by personal and cultural concerns about discussing death, technological challenges, and limited training and incentives for the medical professionals involved. <http://bit.ly/2FvFJ05>

#### **Specialist Publications**

“‘**We cannot let them die**’”: **Undocumented immigrants and media framing of health deservingness in the U.S.**’ (p.14), in *Quality Health Research*.

Cont.

1. 'Tracking Improvement in the Care of Chronically Ill Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life,' June 2013 (noted in 11 June 2013 issue of Media Watch, #310, p.4). **Download/view at:** <http://bit.ly/2FDWI74>

#### Related

- NEW JERSEY | NJ Today – 27 March 2019 – '**New Jersey lawmakers OK physician assisted suicide.**' New Jersey's Medical Aid in Dying for the Terminally Ill Act has been approved by the Assembly and Senate... The Act will authorize medical aid in dying for terminally ill adults with less than six months to live and found by two doctors to be mentally capable to make this medical decision. The new law would give eligible patients the option to request a prescription for medication they can take to shorten a difficult, painful dying process. <http://bit.ly/2FGzc49>

**N.B.** See 'New Jersey Governor's Advisory Council on End-of-Life Care: Report and Recommendations,' Department of Health, November 2018 (noted in 3 December 2018 issue of Media Watch, #593, pp.4-5): **Download/view at:** <http://bit.ly/2U0jmdd>; 'End-of-Life Care Strategic Plan for New Jersey,' New Jersey Health Care Quality Institute, 2018 (noted in 18 June 2018 issue of the weekly report, #568, p.3): **Download/view at:** <http://bit.ly/2HRH6Jk>.

#### **Comprehensive hospice policy brief demonstrating value of Medicare's first "coordinated care" model**

NATIONAL HOSPICE & PALLIATIVE CARE ORGANIZATION | Online – 26 March 2019 – The Association has announced the publication of 'Hospice: Leading Interdisciplinary Care,' a policy brief outlining key aspects, goals, and benefits of hospice care. The document ... is intended to serve as a comprehensive guide for policymakers and stakeholders who seek to learn more about the Medicare Hospice Benefit and understand why integrated, person-centered care model should be adopted more broadly in America's evolving healthcare landscape. Through evidence-based quantitative research and extensive case-study analysis, the policy brief illustrates the physical, emotional, spiritual and financial benefits of hospice care for patients, families, and communities throughout the country. The document also provides research showing that hospice care is cost-effective for Medicare and its beneficiaries. By avoiding expensive treatments and procedures solely designed to prolong the life of terminally-ill patients, hospice users save Medicare dollars while still receiving quality, patient-preferred, end-of-life care on their own terms. The paper also provides important policy considerations to expand access and availability of this critical model of care. <http://bit.ly/2Fu5spH>

**N.B.** Link to Association's report embedded in this report.

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

Representative sample of recent news media coverage:

- MARYLAND | *The Baltimore Sun* – 27 March 2019 – '**Bill to legalize medically assisted suicide in Maryland defeated in state Senate.**' A measure that would have legalized medically assisted suicide in Maryland was defeated on a dramatic tie vote in the state Senate. The bill, known as the 'End of Life Options Act,' had failed three times before in the Maryland General Assembly. But it gained momentum this year, with the House of Delegates approving the measure following an intense and emotional debate. The measure faced more scrutiny in the Senate, where a committee added further requirements for patients and doctors. The bill was changed so much that some advocates for the bill worried that few patients would have been able to request medication from doctors. <http://bit.ly/2JLdpw4>
- MASSACHUSETTS | Mass Live (Springfield) – 26 March 2019 – '**Massachusetts court considers whether to legalize physician-assisted suicide.**' Massachusetts voters in 2012 narrowly rejected an attempt to legalize physician-assisted suicide. The Legislature has repeatedly declined to take it up. Now, advocates of physician-assisted suicide, also called medical aid in dying, are trying to legalize it through the courts. The attorney general's office says it should be up to the Legislature, not the court, to make that decision. The issue has never before been considered by a Massachusetts court, and it is likely to end up before the Supreme Judicial Court. Similar cases in other states have failed to legalize physician-assisted suicide. <http://bit.ly/2YEJmts>

## International

### **Providing comfort: Initiating palliative care in developing countries**

*BORGEN MAGAZINE* | Online – 30 March 2019 – Globally, diagnoses of cancer and other chronic diseases are growing, yet 80% of the world does not have access to sufficient pain management. Morphine, listed by the World Health Organization as an essential pain-relieving drug, costs very little to manufacture. However, more than 150 countries, including 5 million people with terminal cancer, still do not have access to this cheap and efficient pain management option. Of the nearly 58 million people who die every year, 45 million die in developing countries. Factoring in chronic illness statistics, it is estimated that 60% of those who die in developing countries would benefit from proper palliative care. A large part of the issue in procuring pain-relieving medications such as morphine lies in the extremely restrictive policies of many developing nations. For countries such as Egypt, India and Colombia, the attack on addiction and illicit use of morphine have become so great that it is affecting the ability for chronically ill patients to receive the drug. In 2008, morphine in India was

so heavily restricted that only 4% of the 1 million people suffering from cancer were able to receive pain relief treatment. <http://bit.ly/2uBtRoo>

#### **Opioid pain relief in different countries**

**U.S.** gets 30 times more opioid pain relief medication than it needs

**Mexico** gets only 36% of what it needs

**China** gets about 16% of what it needs

**India** gets 4% of what it needs

**Nigeria** gets just 0.2% of what it needs

**Source:** *The Lancet* Commission on Global Access to Palliative Care & Pain Relief: <http://bit.ly/2Gd7oVs>

**N.B.** 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, October 2017 (noted in 16 October 2017 issue of *Media Watch*, #534, p.14). **Full text:** <http://bit.ly/2Ww8Cku>

### **Kerala Planning Board approves revised guideline on community-based palliative care projects**

INDIA | *The New Indian Express* (Chennai, Tamil Nadu) – 29 March 2019 – The Board has given approval to a revised guideline on palliative care (PC)... Local bodies have been asked to provide a three-day training session to those volunteers who are selected for home care. Also, the home care team has been directed to work closely with those medical teams attending patients in the hospital. In the new guideline, the role of nurses and physiotherapists trained in PC has also been included. The palliative management committee that has been formed under each local body will have to ensure that the home care programme is being implemented successfully... It has been found that for the self-evaluation of pain and PC projects in their respective areas, standing committees for health/education/welfare have also been asked to include PC as a separate agenda during their meetings. The other major recommendation the guideline put forward is directing the district panchayats [a unit of local government], municipalities, corporations and block panchayats to ensure better PC initiatives at health institutions in their jurisdiction. <http://bit.ly/2FBkgTv>

### **Edinburgh palliative care patients try out virtual reality “trips” in Scotland first**

U.K. (Scotland) | *Edinburgh News* – 27 March 2019 – Residents of an Edinburgh hospice are the first palliative care patients in Scotland to experience virtual reality through a new university project. The interactive initiative, which can virtually transport patients to locations across the world, will look at the impact of virtual reality (VR) on patients' health and wellbeing. An initial group of six patients at St Columba's Hospice benefitted from the transformative effects of VR when they were offered the chance to revisit some of their favourite places, or explore a part of the world they had never seen. Using the latest high-tech VR headsets, one individual was transported to Jerusalem, a place he had always dreamed of visiting. In another session, a 101-year-old lady revisited her childhood home in Darjeeling and indulged in a first “trip” up the Amazon river. The experience is said to have triggered happy memories with the opportunity to reminisce about old times, as well as enjoying encountering new places. <http://bit.ly/2YznsaG>

## Report finds family rooms should be the norm in all new hospital builds

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 26 March 2019 – Family rooms should be the norm, and not a luxury, in all new hospital builds as part of a move to improve end-of-life (EoL) care, a new report has found.<sup>1</sup> These rooms should provide sources of “positive distraction” ... The report analyses the impact of an initiative by the Irish Hospice Foundation to improve all aspects of EoL and bereavement care in Irish hospitals. The report looked at 18 of 40 projects where physical spaces were transformed so that families could feel respected when dealing with bereavement. In relation to family rooms, it said there should be two types: one at the heart of each ward for families that need a break from the bedside; a second larger room off the ward which is fully-serviced and self-contained for families to stay over, shower and have sustenance. <http://bit.ly/2uqplU6>

1. ‘Evaluation of the Design & Dignity Programme,’ Irish Hospice Foundation, March 2019. **Download /view at:** <http://bit.ly/2uqxWeW>

## Specialist Publications

### Incorporating older adults as “trained patients” to teach advance care planning to third-year medical students

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* – 25 March 2019 – Advance care planning (ACP) is a critical component of end-of-life (EoL) care, yet infrequently taught in medical training. The authors designed a novel curriculum that affords third-year medical students (MS3s) the opportunity to practice EoL care discussions with a trained older adult in the patient’s home. Volunteers were instructed as trained patients (TPs) to evaluate MS3s interviewing and communication skills. The MS3s received a didactic lecture and supplemental material about ACP. Pairs of MS3s conducted ACP interviews with TPs who gave verbal and written feedback to students. Student evaluations included reflective essays and pre-/post-surveys in ACP skills. Qualitative analysis of reflective essays revealed four themes: 1) Students’ personal feelings, attitudes, and observations about conducting ACP interviews; 2) Observations about the process of relationship building; 3) Learning about and respecting patients’ values and choices; and, 4) The importance of practicing the ACP skills in medical

school. Students’ confidence in skills significantly improved in all seven domains: 1) Introduce subject of EoL; 2) Define advance directives; 3) Assess values, goals, and priorities; 4) Discuss prior experience with death; 5) Assess expectations about treatment and hospitalization; 6) Explain cardiopulmonary resuscitation and outcomes; and, 7) Deal with own feelings about EoL and providers’ limitations. **Abstract:** <http://bit.ly/2HJ0wRb>

### Publishing Matters

‘Knowledge and motivations of researchers publishing in presumed predatory journals: A survey’ (p.16), in *BMJ Open*.

‘A model for public access to trustworthy and comprehensive reporting of research’ (p.16), in *Journal of the American Medical Association*.

‘Plagiarism detectors are a crutch, and a problem’ (p.16), in *Nature*.

### Related

- *BRITISH MEDICAL JOURNAL* | Online – 29 March 2019 – ‘GPs must pass on patients’ advance treatment decisions to hospitals, says judge.’ A High Court judge [in the U.K.] has told GPs that if they have in their files an advance decision on treatment made by a patient before losing capacity, they must pass it on to any hospital treating the patient. Justice Hayden gave the warning when ruling that a patient in a persistent vegetative state who had been kept alive for three years, despite an advance decision refusing all treatment, should have treatment withdrawn and be allowed to die. He said that he delayed publishing his judgment until a month after her death to allow her family to grieve in privacy. **Full text:** <http://bit.ly/2WAkp0r>

## The price of loss: A literature review of the psychosocial and health consequences of childhood bereavement

*BEREAVEMENT CARE* | Online – 27 March 2019 – Over the past decade, there has been an increasing level of consensus among researchers that the loss of a parent in childhood can have all-encompassing consequences. Bereaved children have an increased risk of developing psychological, physical, and social challenges in life. These challenges can, in cases relating to life-threatening illnesses, already be identified in the time proceeding the loss ... as well as in the time period following bereavement... Although the majority of these challenges are reduced over time, others persist. The authors investigate the short to medium and long-term consequences [before the age of 18] of losing a parent as a child through a literature analysis primarily based on the last two decades

of research. This is accomplished through the presentation of studies that have explored the psychological, physical, social, and health-related consequences of parental loss in childhood. This review focuses on presenting selected research literature and discussing both the limitations and the quality of these studies. **First page view:** <http://bit.ly/2HMLcGW>

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Virtual Hospice  Portail CANADIEN EN SOINS  
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Supporting Grieving or Bereaved Children  
<http://bit.ly/2sQ2bLy>

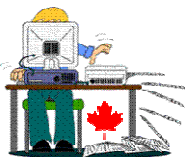
### Related

- *HEALTHCARE* | Online – 20 March 2019 – **‘Parental life-limiting illness: What do we tell the children?’** An important aspect of the patient’s psychosocial care should include recognition their children are also likely to experience severe stress because of the illness. This study aims to increase understanding of children’s experiences when a parent has a life-limiting illness by exploring bereaved children’s experiences of the support they received when their parent had a life-limiting illness, and professionals’ perspectives of the support offered to children. Children report needing open, clear and age appropriate conversations with parents and health care professionals (HCPs) to help them begin to obtain some meaning from the situation. The importance of communication is discussed, with particular reference to the role HCPs have in supporting these conversations. **Abstract:** <http://bit.ly/2TWPAG6>

**N.B.** Click on pdf icon to access full text.

Noted in Media Watch 5 November 2018 (#588, p.12):

- *PALLIATIVE MEDICINE* | Online – 29 October 2018 – **‘Health and social care professionals’ experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis.’** A literature search yielded 15,758 articles. Fifteen met the authors’ inclusion criteria. Thirteen included professionals’ experiences of supporting parents and children before parental death. Two included experiences of supporting surviving parents and children afterwards. Themes identified: 1) Aspiring to deliver family-focussed care; 2) Health and social care professionals’ behaviours and emotion; and, 3) Improving connections with parents and children. Professionals struggle to connect empathically with parents and their children to prepare and support children when a parent is dying and afterwards. **Abstract:** <http://bit.ly/2HCG9oU>



### [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>

## Multiple and multi-dimensional life transitions in the context of life-limiting health conditions: Longitudinal study focusing on perspectives of young adults, families and professionals

*BMC PALLIATIVE CARE* | Online – 25 March 2019 – This study is unique in that it captures the voices of young adults (YAs) with life-limiting conditions, including those with very little functional verbal communication. Further, the data were captured over time, and went beyond the focus of previous studies on health transitions by situating it within holistic life transitions. It also looked at the impact of one transition on other transitions. It challenges the notion that all life transitions are triggered by health transitions, and has highlighted attitudinal and systemic factors that can be changed to facilitate smoother transitions. Also, as anticipated, we found that transitions of others (e.g., family members, peers and professionals) have the potential to trigger other transitions for them. Similarly, the authors found that significant others were experiencing multiple and multi-dimensional transitions, some of which were linked with the YAs' transitions. For some, there was evidence of holding back from certain transitions and/or feel-

ing guilty about moving on when the YA was unable to do so or required their support. Others had speeded up their transitions such as in the case of people who had retired early or stopped working to look after their child/grandchild. **Full text:** <http://bit.ly/2HHYPnj>

### Extract from *BMC Palliative Care* article

[The authors] argue that transition from children's hospices or similar services to adult services should be based on their development stage rather than their biological age. Other organisations, in partnership with children's hospices, might be able to provide stage related services that they were used to in children's hospices but are not normally provided by adult services. An example would be an accessible accommodation for short planned breaks as YAs and families found this to be a really useful service offered by children's hospices.

## Preventive drugs in the last year of life of older adults with cancer: Is there room for deprescribing?

*CANCER* | Online – 25 March 2019 – A nationwide cohort study of older adults ... with solid tumors who died between 2007 and 2013 was performed in Sweden... The authors calculated the monthly use and cost of preventive drugs throughout the last year before the patients' death. Among 151,201 older persons who died with cancer (mean age 81.3...), the average number of drugs increased from 6.9 to 10.1 over the course of the last year before death. Preventive drugs frequently were continued until the final month of life, including antihypertensives, platelet aggregation inhibitors, anticoagulants, statins, and oral antidiabetics. Median drug costs amounted to \$1,482 ... per person, including \$213 ... for preventive therapies. Compared with older adults who died with lung cancer..., costs for preventive drugs were higher among older adults who died with pancreatic cancer ... or gynecological cancers... There was no decrease noted with regard to the cost of preventive drugs throughout the last year of life. Adequate deprescribing strategies are warranted to reduce the burden of drugs with limited clinical benefit near the end of life. **Abstract:** <http://bit.ly/2HFRHro>

### Related

- *CANADIAN JOURNAL ON AGING* | Online – 27 March 2019 – '**Reducing potentially inappropriate medications in older adults: A way forward.**' De-prescribing, an initiative to reduce the use of potentially inappropriate medications (PIMs), has gained importance in improving appropriate prescribing practices. It is a methodical approach to gradually stopping inappropriate medications judiciously for each patient and simultaneously monitoring the patient carefully for the onset of adverse events or rebound symptoms. A combined caregiver-patient-centred approach encourages the collaboration between prescribers and pharmacists to reduce PIMs in older adults. **Abstract:** <http://bit.ly/2Ww3hsz>

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Would this article be of interest to a colleague?

Noted in Media Watch 25 March 2019 (#607, p.9):

- *EUROPEAN GERIATRIC MEDICINE* | Online – 15 March 2019 – ‘**Prescription and deprescription of medications for older adults receiving palliative care during the last three months of life: A single-center retrospective cohort study.**’ This study highlights the preferential prescription of essential drugs and deprescription of unnecessary drugs during the last three months of life in older adults. However, palliative care (PC) occurs principally during the last week of life and a high burden of unnecessary drugs is still found on the day of death. Both earlier implementation of PC and an improvement of prescribing practices are needed by setting up interventions to raise awareness and promote early physician-patient communication about care goals and potential benefits of deprescribing unnecessary drugs. **Abstract (w. list of references):** <http://bit.ly/2Y5JySb>

**N.B.** Additional articles on medications with questionable benefit at the end of life noted in 26 November 2018 issue of Media Watch (#591, p.6).

### **Palliative care and end-stage liver disease: A critical review of current knowledge**

*CURRENT OPINION IN GASTROENTEROLOGY* | Online – 28 March 2019 – End-stage liver disease (ESLD) is associated with high symptom burden, poor quality of life, and significant healthcare costs. Palliative care (PC), which is not synonymous with hospice or end-of-life care, is a multidisciplinary model of care that focuses on patient-centered goals with the intent of improving quality of life and reducing suffering. Advance care planning (ACP) and goals of care discussions have been associated with improved quality of life, decreased anxiety, and improved satisfaction with care for both the patient and the caregiver. These discussions are beneficial to all patients with ESLD, including those listed for liver transplantation. Despite the resounding benefits of PC for patients with other advanced diseases, PC remains underutilized in liver disease. There is an urgent need for education of hepatology/transplant providers as well as development of society guidelines to help dissemination and acceptability of PC for patients with ESLD. **Abstract:** <http://bit.ly/2V4Sfub>

**N.B.** Additional articles on PC and end-stage liver disease noted in 25 March 2019 issue of Media Watch (#607, p.9).

### **Parental life-limiting illness: What do we tell the children?**

*HEALTHCARE* | Online – 20 March 2019 – Being diagnosed with and having a life-limiting illness is a stressful experience which is compounded when the patient has dependent children. An important aspect of the patient’s psychosocial care should include recognition that their children are also likely to experience severe stress because of the illness. However, children’s needs are often overlooked during the illness. These needs include information about the illness. Healthcare professionals (HCPs) have a significant role in supporting patients to communicate with their children. This study aims to increase understanding of children’s experiences when a parent has a life-limiting illness by exploring bereaved children’s experiences of the support they received when their parent had a life-limiting illness, and professionals’ perspectives of the support offered to children. Children report needing open, clear and age appropriate conversations with parents and HCPs to help them begin to obtain some meaning from the situation. **Abstract:** <http://bit.ly/2TWPAG6>

**N.B.** Click on pdf icon to access full text.

Noted in Media Watch 5 November 2018 (#588, p.12):

- *PALLIATIVE MEDICINE* | Online – 29 October 2018 – ‘**Health and social care professionals’ experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis.**’ A literature search yielded 15,758 articles. Fifteen met the authors’ inclusion criteria. Thirteen included professionals’ experiences of supporting parents and children before parental death. Two included experiences of supporting surviving parents and children afterwards. Themes identified: 1) Aspiring to deliver family-focussed care; 2) Health and social care professionals’ behaviours and emotion; and, 3) Improving connections with parents and children. Professionals struggle to connect empathically with parents and their children to prepare and support children when a parent is dying and afterwards. **Abstract:** <http://bit.ly/2HCG9oU>



## Focus on ethics and palliative care in the intensive care unit

*INTENSIVE CARE MEDICINE* | Online – 25 March 2019 – This editorial highlights papers on prognostic and palliative care (PC) strategies for critically ill patients and their families that were published in *Intensive Care Medicine (ICM)* and other journals in the last two years, including five original research papers, one systematic review, one pragmatic review, six “what’s new,” two “understanding the disease,” and one editorial. The past several decades of critical care research have led to numerous treatment and technological advances resulting in improved ICU survival, but interventions to improve patient- and family-centered care have not kept pace. However, emerging literature suggests there is a renewed focus on comprehensive approaches to critical care grounded in partnerships between patients, families, and healthcare professionals. A key component of such efforts is highlighted in a recently published *ICM* editorial that provides ten evidence-based principles of PC in the ICU.<sup>1</sup> This framework builds on the recognition that the highest quality critical care is provided simultaneously with, not independently from, PC for all critically ill patients to address symptoms, communication about goals of care, family support, shared decision-making, and in some cases, dying. **Full text:** <http://bit.ly/2CAVyBN>

1. ‘Ten key points about ICU palliative care,’ *Intensive Care Medicine*, 2017;43(1):83-85. **Introduction (w. list of references):** <http://bit.ly/2YuRPz1>

Noted in Media Watch 11 March 2019 (#605, p.9):

- *INTENSIVE CARE MEDICINE* | Online – 7 March 2019 – ‘**Eight things we would never do regarding end-of-life care in the ICU.**’ As intensivists from three distinct regions of the world [i.e., the U.S., France, Israel] with different cultural backgrounds, the authors believe it relevant in this rapidly emerging period of healthcare to share thoughts among clinicians providing end-of-life care (EoLC) in the intensive care unit. This article presents the authors’ vision of eight top-tier concepts that should be embraced to usher in the best EoLC for all patients. The authors realize that not everyone will agree with these points and anticipate that our “eight things” will stimulate healthy discussion and debate. **Abstract (w. list of references):** <http://bit.ly/2XHEB1L>

## End-of-life care in an Australian acute hospital: A retrospective observational study

*INTERNAL MEDICINE JOURNAL* | Online – 25 March 2019 – A retrospective observational study of consecutive adult inpatient deaths between 1 July 2010 and 30 June 2014 in four different medical units of an Australian tertiary referral hospital was performed. Units were selected on the basis of highest inpatient death rates and included medical oncology, respiratory medicine, cardiology and gastroenterology/hepatology. Overall, 41% of patients died with active medical treatment plans, but significantly more respiratory and cardiology patients died with ongoing treatment (46% and 75% respectively) than medical oncology and gastroenterology patients (each 27%...). More medical oncology and gastroenterology patients were recognised as dying (92% and 88%) compared to 72% of respiratory and only 38% of cardiology patients... Significantly more medical oncology patients were referred to palliative care (PC) and received comfort care plans than all other patient groups. However, the rate of non-palliative interventions given in the final 48 hours was not significantly different between all four groups. There were differences in managing the dying process between all disciplines. A possible solution to these discrepancies would be to create an integrated PC approach across the hospital. **Abstract:** <http://bit.ly/2CBMm06>

## Association of expanded Veterans Affairs hospice care [in the U.S.] with aggressive care and cost for veterans with advanced lung cancer

*JAMA ONCOLOGY* | Online – 28 March 2019 – Is increased availability of hospice for veterans associated with reduced aggressive treatments and medical care costs at the end of life? In this cohort study of 13,085 veterans, those with newly diagnosed end-stage lung cancer treated at Veterans Affairs Medical Centers (VAMCs) with the most expansion in hospice use had a significantly greater likelihood of re-

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ceiving chemotherapy or radiation therapy after hospice enrollment but a lower likelihood of having aggressive treatment or intensive care unit use, compared with similar veterans treated in VAMCs with low hospice growth. Increasing hospice availability without restricting treatment access for veterans with advanced lung cancer was associated with less aggressive medical treatment and significantly lower medical costs while still enabling veterans to receive cancer treatment. **Abstract:** <http://bit.ly/2U44uKY>

#### Related

- *JAMA ONCOLOGY* | Online – 28 March 2019 – ‘**Hospice and anticancer therapy – shifting from an either/or to a both/and treatment model.**’ In the U.S., the Medicare Hospice Benefit was established in 1982, providing hospice coverage to Medicare beneficiaries who have life expectancies of 6 months or less and have decided to forgo curative treatments. The U.S. health care insurance plans have adopted similar coverage models, including hospice coverage for veterans with terminal illness by the U.S. Veterans Affairs in 1991. In the ensuing decades, hospice care has grown in scope. In the U.S., an estimated 1.7 million patients received hospice services in 2014, and 43% of Medicare decedents in 2013. **Abstract:** <http://bit.ly/2OuZ0CM>

#### Dying with dementia: Under-recognized and stigmatized

*JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 25 March 2019 – 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>

#### Extract from *Journal of the American Geriatrics Society* article

Despite the high prevalence of dementia at the end-of-life, discussions about dementia rarely acknowledge its terminal nature. In the 115 pages of the [U.S.] ‘National Plan to Address Alzheimer’s Disease: 2018 Update,’ the term “death” appears just twice, “hospice” once, and “palliative care” four times.<sup>1</sup>

1. ‘National Plan to Address Alzheimer’s Disease: 2018 Update,’ U.S. Department of Health & Human Services. **Download/view at:** <http://bit.ly/2uv971r>

Noted in Media Watch 18 March 2019 (#606, p.2):

- U.S. | CNN – 14 March 2019 – ‘**Deaths from dementia have more than doubled in U.S., report says.**’ A by the National Center for Health Statistics shows that the rate of Americans who died from dementia has more than doubled from 30.5 deaths per 100,000 people in 2000 to 66.7 in 2017.<sup>1</sup> The term dementia encompasses disease states that impair memory and result in a decline in cognitive function. These conditions seem to be affecting more of the population as it is expected to affect 14 million people age 65 and older by 2060, according to the U.S. Centers for Disease Control & Prevention (CDC).<sup>2</sup> Alzheimer’s disease accounted for 46% of the 261,914 deaths due to dementia in the U.S. in 2017. <https://cnn.it/2W0yWls>
  1. ‘Dementia Mortality in the U.S., 2000-2017,’ National Vital Statistics Report, 2019;68(2), National Center for Health Statistics. **Download/view at:** <http://bit.ly/2O7sWVG>
  2. ‘What is the burden of Alzheimer’s disease in the U.S.?’ U.S. Centers for Disease Control & Prevention. **Download/view at:** <http://bit.ly/2XZULDV>

**N.B.** Selected articles on palliative and end-of-life (EoL) care for people living with Alzheimer’s and other forms of dementia noted in several past issues of Media Watch, for example, 7 January 2019 (#596, pp.9-10), and 10 and 31 December 2018 (respectively, #593, p.7 and #595, p.16). Articles on advance care planning, advance directives and EoL decision-making for people living with Alzheimer’s disease and other forms of dementia noted in 4 March 2019 issue of Media Watch (#604, p.13).

## National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition: Why is this important to chaplains?

*JOURNAL OF HEALTH CARE CHAPLAINCY* | Online – 27 March 2019 – Through the involvement of the Association of Professional Chaplains and the HealthCare Chaplaincy Network, this is the first time that any chaplains have been an official party to the development of these guidelines.<sup>1</sup>



The expectation set by the guidelines is that all healthcare professionals (including all chaplains) caring for people living with serious illness at any stage of illness, at any age, and in any setting will integrate core palliative care principles and best practices into their routine care and have sufficient training to complete an assessment of the patient and address common sources of suffering. This article presents a summary of the content of the guidelines and their implications for clinical practice and training with emphasis on the practice and training of professional chaplains. **Abstract:** <http://bit.ly/2FGcLf4>

1. 'National Consensus Project's Clinical Practice Guidelines for Quality, Palliative Care, 4th Edition,' National Consensus Project for Quality Palliative Care, 2018. **Download/view at:** <http://bit.ly/2uulDhJ>

Noted in Media Watch 5 November 2018 (#588, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 31 October 2018 – 'A systematic review in support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care.' This systematic review highlights the large and varied body of research that exists in palliative care (PC). Most promising areas in terms of structure and process of care are home-based PC, interdisciplinary team care, and telehealth approaches. This comprehensive review underscores the importance of targeting future research toward building high-quality evidence in key areas of clinical practice and patient/caregiver needs. **Full text:** <http://bit.ly/2HK3apR>

**N.B.** Additional articles on the role of chaplains in PC noted in 22 October 2018 issue of Media Watch (#586, pp.5-6).

## Models of outpatient palliative care clinics for patients with cancer

*JOURNAL OF ONCOLOGY PRACTICE* | Online – 25 March 2019 – In the 2016 clinical guideline, American Society of Clinical Oncology recommended integrating palliative care (PC) early in the disease trajectory alongside cancer-directed treatment.<sup>1</sup> Despite strong endorsement and robust evidence of benefit, many patients with cancer lack access to outpatient PC. The authors define different models of care delivery in successful PC clinics in four distinct healthcare settings: an academic medical center, a safety net hospital, a community health system, and a hospice-staffed clinic embedded in a community cancer center. This summary of key aspects of functional outpatient PC clinics will enable healthcare institutions to evaluate their specific needs and develop programs that will be successful within the environment of an individual institution. **Abstract:** <http://bit.ly/2FAi28f>

1. 'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,' *Journal of Clinical Oncology*, 2017;35(1):96-112 (noted in 31 October 2016 issue of Media Watch (#486, p.7). **Full text:** <http://bit.ly/2utXVSB>

Noted in Media Watch 18 February 2019 (#602, p.10):

- *CURRENT TREATMENT OPTIONS IN ONCOLOGY* | Online – 11 February 2019 – 'Palliative cancer care in the outpatient setting: Which model works best?' There are currently many variations for how palliative care (PC) is delivered in the outpatient setting, including: 1) Interdisciplinary specialist PC in stand-alone clinics; 2) Physician-only specialist PC in stand-alone clinics; 3) Nurse-led specialist PC in stand-alone clinics; 4) Nurse-led specialist PC telephone-based interventions; 5) Embedded specialist PC with variable team makeup; and, 6) Advanced practice providers-based enhanced primary PC. It is important to make a clear distinction among these delivery models of outpatient PC because they have different structures, processes, and outcomes, along with unique strengths and limitations. **Opinion statement (w. list of references):** <http://bit.ly/2USApKb>

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## Related

- *JOURNAL OF SURGICAL ONCOLOGY* | Online – 20 March 2019 – ‘**Evidence for integration of palliative care into surgical oncology practice and education.**’ High-quality data support multiple clinical benefits of integrating palliative care (PC) into routine oncology care. Though these data come largely from the medical oncology literature, data from surgical oncology populations support similar associations between PC integration and improved clinical outcomes, all without compromise in survival. In this article, the authors review data supporting PC integration into oncology care, with a focus on surgical populations and recommendations for incorporating PC into surgical oncology. **Abstract:** <http://bit.ly/2YpqHlb>

### **Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 March 2019 – Palliative care (PC) will play an important role to alleviate disease suffering and improve quality of life for cancer patients and their family caregivers. The authors identified 3,194 [survey] respondents ... who met the inclusion criteria. About 71% (2,097) of all respondents had no knowledge of PC. 84.5% of Hispanic respondents had no knowledge of PC. Multivariable analyses indicated the middle-aged (50-64 years old...) and elder population (65 years or older...) have a significantly better knowledge of PC than those under age 50. Common misconceptions existed in respondents, even those who had self-reported adequate knowledge of PC. The proportion of adults who have knowledge of PC is low in the U.S.. Greater efforts are needed to promote PC and reduce the misconceptions of PC in the general population. **Abstract (inc. link to references):** <http://bit.ly/2JCTteG>

### **Predicting those who are at risk of dying within six to twelve months in primary care: A retrospective case-control general practice chart analysis**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 March 2019 – Cases were patients aged  $\geq 70$  years who had died in the previous 5 years. The most predictive patient characteristics of a risk of death within 6 to 12 months were: deteriorating performance status, weight loss, persistent symptoms, request for palliative care or treatment withdrawal, impaired activities of daily living, falls  $\pm$  fractured hip, neurological deterioration, advanced lung disease, and estimated glomerular filtration rate ... with deteriorating health. The Supportive & Palliative Care Indicators Tool demonstrated a sensitivity and specificity of 67% and 87%, respectively, with a predictive accuracy of 78%. **Abstract:** <http://bit.ly/2uBWC4a>

### **Top ten tips palliative care clinicians should know about psychopharmacology**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 March 2019 – Palliative care (PC) providers often prescribe psychotropic medications to address psychological and physical suffering of patients with serious medical illness. Consideration must be given to the significant medical comorbidities of the patient when selecting a medication. This article seeks to provide guidance on how to safely and effectively select a psychotropic agent for depression, anxiety, and other distressing symptoms for patients with serious illness. To do so, the authors draw upon a team of physicians and a pharmacist with training in psychiatry and PC to highlight the “Top 10” tips for selecting a psychotropic medication to provide relief for patients with serious medical illness. **Abstract:** <http://bit.ly/2ClqCQe>

### **Pediatric palliative care**

### **Finding hope and healing when cure is not possible**

*MAYO CLINIC PROCEEDINGS* | Online – 25 March 2019 – As patients and their families affected by incurable disease navigate the complex journey of healing, and as the nature of their hopes evolves in profound ways, clinicians can play a crucial role. This involves knowing when to give gentle guidance,

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when to speak and when not to say a word, when to intervene (and to what degree), and when to get out of the way. In the best of circumstances, the healing power of a clinician's presence may complement, although it can never match, the devotion of parents to their dying child. Nevertheless, clinicians can learn to sense opportunities in reports of patients' symptoms, help them reframe those perceptions with gentleness and persistence, develop the courage to accompany people through dark passages, and recognize freedom as an ultimate goal. All of these discoveries help foster healing. They can empower patients, parents – and clinicians – to find life on the other side of despair. **Full text:** <https://mayocl.in/2Ov1CRf>

### **Palliative care and inpatient neurology. Where to next?**

*NEUROLOGY* | Online – 27 March 2019 – Palliative care (PC) is an approach to the care of persons with serious illness that focuses on reducing suffering by attending to medical symptoms, psychosocial issues, spiritual well-being, and planning for the future. While PC is often associated with hospice (PC for persons nearing end of life) and cancer, PC has a broader scope, may be helpful at any point along an illness trajectory, may be provided by non-PC specialists (so called primary PC), and is useful for patients with non-cancer diagnoses, including neurologic illness. Although the potential value of the PC approach for patients affected by acute and chronic neurologic illness has been recognized for 20 years, there has been a spike in interest in this topic over the past 5 years, including the emergence of neuropalliative care as a defined sub-specialty. As this field grows, so does the need for empirical research to guide clinical, educational, and research efforts. **Abstract:** <http://bit.ly/2JNTiNE>

#### **Related**

- *NEUROLOGY* | Online – 27 March 2019 – ‘**Inpatients with neurologic disease referred for palliative care consultation.**’ [In this study] the most common reason for palliative care (PC) consultation in all patients was assistance with goals-of-care and advanced care planning. PC consultation was less often requested for pain and symptom management in patients with neurologic disease compared to patients with cancer and more often for assistance with transition to comfort measures only and withdrawal of life-sustaining treatment. Patients with cancer had higher Palliative Performance Scale scores and were more likely to be discharged home from the hospital, while patients with neurologic disease were more likely to die in hospital. **Abstract:** <http://bit.ly/211K267>

### **Innovative project aims to support home-based palliative care**

*NEWSGP* | Online – 26 March 2019 – The majority of palliative patients in Australia would prefer to be cared for and to die at home. For most of these people, however, those wishes will not be fulfilled. caring@home is a national palliative care (PC) project aimed to fill this service gap by delivering innovative models of care via a suite of free, standardised and best-practice education resources to individual carers and community services that provide PC. These resources also incorporate training modules to support carers in managing symptoms of PC patients safely, using subcutaneous medicines. The caring@home project team emphasises that it is not about replacing the important role of community healthcare professionals in the delivery of at-home PC. Rather, the project is designed to augment those roles to improve PC services to patients who want to die at home, and involves their carers in breakthrough symptom management, while the patient is still supported by nurses and their GP. **Full text:** <http://bit.ly/2YtWt0z>

#### **Related**

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 28 March 2019 – ‘**Perceptions of a home hospice crisis: An exploratory study of family caregivers.**’ Crises that occur in home hospice care affect family caregivers' satisfaction with care and increase risk of disenrollment. Because hospice care focuses on achieving a peaceful death, understanding the prevalence and nature of crises that occur in this setting could help to improve end-of-life outcomes. Of the 183 participants, 76 (42%) experienced a perceived crisis, while receiving hospice care. Three types of crises emerged: patient signs and symptoms, patient and/or caregiver emotional distress, and caregiver burden. Women were more likely than men to report a crisis. **Abstract:** <http://bit.ly/2OuZ0CM>

## **Appropriate frameworks for economic evaluation of end-of-life care: A qualitative investigation with stakeholders**

*PALLIATIVE MEDICINE* | Online – 27 March 2019 – The objective of this study was to elicit the views of expert stakeholders on the purpose and evaluation of supportive end-of-life (EoL) care, and explore how different purposes of EoL care imply the need for different evaluative frameworks. The authors interviewed twenty professionals working in or visiting the U.K. or Republic of Ireland, with clinical experience and/or working as academics in health-related disciplines. Four purposes of EoL care were identified from, and are critiqued with, the aid of the qualitative data to: 1) Improve health; 2) Enable patients to die in their preferred place; 3) Enable the patient to experience a good death; and; 4) Enable the patient to experience a good death, and those who are close to the patient to have an experience which is as free as possible from fear, stress and distress. Managing symptoms and reducing anxiety were considered to be core objectives of EoL care and fit with the wider health service objective of improving/maximising health. A single objective across the entire health system ensures consistency in the way that resource allocation is informed across that entire system. However, the purpose of care at the EoL is more complex, encompassing diverse and patient-centred objectives which the authors have interpreted as enabling the patient to experience a good death. **Abstract:** <http://bit.ly/2OxHj5w>

## **Patient-provider care goal concordance: Implications for palliative care decisions**

*PSYCHOLOGY & HEALTH* | Online – 2 March 2019 – Goal-concordant care is an important feature of high quality medical treatment. Patients' care goals may focus on curative and/or palliative outcomes. Patients rarely communicate their care goals, and providers' predictions of patient goals are often inaccurate, corresponding most closely to their own treatment goals. This projection of own goals onto patients introduces the potential for bias, leading to goal-discordant care. The authors examined goal discordance using data from a U.S. sample of healthcare providers... Providers reported their perceptions of their patients' care goals (curative relative to palliative), their own care goals if they were to become ill, and their willingness to deliver palliative care (PC). For 28% of providers, their own care goals differed from those of their patients. Providers were more likely to prioritise PC – relative to curative – in their own goals than in their predictions about patients' goals. Providers were more willing to deliver PC when their own goals prioritised more palliative relative to curative care, but their perceptions of patient goals were unassociated with willingness to provide it. Efforts to improve goal communication and reduce projection biases among providers may facilitate goal-concordant care. **Abstract:** <http://bit.ly/2YjFgXI>

Noted in Media Watch 23 May 2018 (#463, p.12):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 May 2016 – ‘**Good concordance between patients and their non-professional carers about factors associated with a “good death” and other important end-of-life decisions.**’ Only 69% of patients [i.e., study participants] stated they had discussed their preferences for end-of-life (EoL) care with their respective carer. The rankings were similar for the patient and the carer's views of what was important for the patient, although the patients ranked “to be involved in decisions about my care” as less important than the carers, while the carers ranked “to have sorted out my personal affairs” as less important than the patients. When discussions around EoL choices do occur, carers generally appear to agree with the patients' preferences around EoL treatment, and preferred place of death. **Abstract:** <http://bit.ly/2YIFflY>

## **“We cannot let them die”: Undocumented immigrants and media framing of health deservingness in the U.S.**

*QUALITY HEALTH RESEARCH* | Online – 24 March 2019 – Based on a systematic qualitative analysis of articles published by *The New York Times* (2009-2017), this article presents the main media frames that support the access to government-sponsored healthcare by undocumented immigrants, just before and after passage of the U.S. Affordable Care Act in 2010. Under the umbrella of “selective inclusion,” this study highlights a “compassionate frame” that conveys sympathy toward severely ill, undocumented im-

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migrants. This approach is reinforced by a “cost-control” frame that underlines the economic benefits of providing healthcare to the undocumented immigrant population in the U.S. Supported by both humane and market-based approaches, these frames make a compelling case for the inclusion of particular groups into the U.S. healthcare safety net. Ultimately, these findings contribute to an understanding of the media framing of undocumented immigrants’ right to healthcare on the basis of deservingness. **Abstract:** <http://bit.ly/2JBNGWF>

Noted In Media Watch 7 January 2019 (#596, p.4):

- *AMA JOURNAL OF ETHICS*, 2019;21(1). ‘**Healthcare for undocumented immigrants.**’ Caring for undocumented immigrants, refugees, and asylees requires knowledge of the challenges and barriers to care those patients face. This issue considers the nature and scope of clinicians’ obligations to support and care for undocumented immigrants, refugees... **Journal contents page:** <http://bit.ly/2YiYTPk>

Noted in Media Watch 21 May 2018 (#564, p.2):

- *KAISER HEALTH NEWS* | Online – 18 May 2018 – ‘**Choosing between death and deportation.**’ What happens when an undocumented immigrant has a life-threatening diagnosis? Much depends on where the person lives. And even in states with generous care for a dire illness, a patient can face difficult life-and-death choices. **Full text:** <http://bit.ly/2Tx4RIT>

### Rational patient apathy

*SETON HALL LAW REVIEW*, 2019;49(3):535-628. Patients with serious or life-threatening illness are frequently asked to make complex, high-stakes medical decisions. The impact of anxiety, low health literacy, asymmetric information and inadequate communication between patients and healthcare providers, family pressures, rational apathy by healthcare providers, cognitive biases of both patients and healthcare providers, and other factors make it quite difficult for patients in these circumstances to process and comprehend the strategic uncertainty and resultant risks and benefits of, and alternatives to, whatever therapeutic or life-prolonging treatment physicians are offering. All of these factors render the classic goal of “informed consent” unachievable in all but the rarest of circumstances: The effort to discuss and evaluate strategic uncertainty, its rational reduction into risks and benefits, and alternatives of treatment for purposes of optimizing decisional outcomes will have genuine intrinsic value only for ultra-

rational patients (and physicians). **Click on pdf icon to access full text at:** <http://bit.ly/2Oz4EnL>

#### Extract from *Seton Hall Law Review* article

Physicians who practice in the curative role tend to focus on clinical problem solving, will continue to advocate for therapy even when the prognosis is grim, and may often view death as a failure. Physicians who practice in the palliative care (PC) role focus on the patient as a whole person rather than as a disease diagnosis and will view unnecessary suffering at the end of life as a failure. Thus, the underutilization of palliative and hospice care in this country represents a missed opportunity on a massive scale. A growing body of evidence demonstrates that an emphasis on PC, in conjunction with carefully considered therapeutic care, can not only improve patients’ quality of life holistically but also provide a significant comparative advantage in prolonging life over standard therapeutic treatment.

### Empathy as care: The model of palliative medicine

*SOCIETY* | Online – 22 March 2019 – This article elaborates the ascent of what the authors call the empathy as care model in contemporary medicine. They make the following arguments: First, does empathy mean care? The authors examine this question in the context of medicine and argue that empathy may not mean care throughout all medical practice, as findings from the medical education field show. However, empathy as care is rising in one specialty, palliative and hospice medicine. This specialty best represents the ideal-typical traits of the empathy as care model. This work contributes to the sociology of health and illness literature and to interpretivist sociological theorizing by examining empathy within the context of health care meant to relieve pain and discomfort, often at the end of life, rather than curative medicine. **Abstract (w. list of ‘Further Reading’):** <http://bit.ly/2WjVnCk>

## Publishing Matters

### **Knowledge and motivations of researchers publishing in presumed predatory journals: A survey**

*BMJ OPEN* | Online – 23 March 2019 – The authors' objective was to develop effective interventions to prevent publishing in presumed predatory journals (i.e., journals that display deceptive characteristics, markers or data that cannot be verified). An online survey was delivered to two sets of corresponding authors containing demographic information, and questions about researchers' perceptions of publishing in the presumed predatory journal, type of article processing fees paid, and the quality of peer review received. The survey also asked six open-ended items about researchers' motivations and experiences. The majority of respondents first encountered the journal via an email invitation to submit an article, or through an online search to find a journal with relevant scope. Most participants indicated their study received peer review and that this was helpful and substantive. More than a third indicated they did not pay fees to publish. This work provides some evidence to inform policy to prevent future re-

search from being published in predatory journals. This research suggests that common views about predatory journals (e.g., no peer review) may not always be true, and that a grey zone between legitimate and presumed predatory journals exists. The results are based on self-reports and may be biased thus limiting their interpretation. **Full text:** <http://bit.ly/2uoTDMr>

#### **Strengths and limitations of this study**

The survey specifically explored researchers' motivations to publish in predatory journals.

The survey targeted biomedical researchers where dissemination of preclinical and clinical outcomes may affect health services and patient care.

The survey is limited by a low response rate from participants.

### **A model for public access to trustworthy and comprehensive reporting of research**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 28 March 2019 – In the U.S. the Patient-Centered Outcomes Research Institute (PCORI) was authorized by Congress in 2010 to fund comparative clinical effectiveness research. The legislation required the institute to guarantee peer review of all research results and to make those results publicly accessible within 90 days of their receipt, requirements that were the first of their kind for a US-based research funding organization. The authorizing legislation further stipulated that the peer review should assess the scientific integrity of each study and its adherence to the methodological standards established by the PCORI methodology committee. The law broadly defined the forms of peer review that would be acceptable. The PCORI board of governors, after comment from patients, clinicians, professional interest groups, and journal editors, established a peer review process requiring all awardees to submit a comprehensive final report for PCORI-based external peer review. After final approval, the institute would post on its website lay and technical abstracts of the report; the complete, approved final report and study protocol; and a summary of the peer review critiques and the authors' responses to those critiques. This Viewpoint describes the peer review system and the comprehensive report, which are the essential elements of this program, and discusses the problems each raise and the potential benefits. **Full text:** <http://bit.ly/2THxMKr>

### **Plagiarism detectors are a crutch, and a problem**

*NATURE* | Online – 27 March 2019 – Software cannot determine plagiarism; it can only point to some cases of matching text. The systems can be useful for flagging up problems, but not for discriminating between originality and plagiarism. That decision must be taken by a person. The most important method for finding plagiarism is reading a text and studying the references for inconsistencies. A spot check with an Internet search engine, using three to five words from a paragraph or a particularly nice turn of phrase can uncover copyists. Searching for a reference that looks odd might turn up a source that mangled the reference in the same manner. Only if a text is somehow off, and online searching does not help, should software systems be consulted. In those cases, it's best to use two or three systems, and to read the reports, not take the numbers at face value. **Full text:** <https://go.nature.com/2WrPp2z>



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

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[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2G2tf1W>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

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