

## Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

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Compiled & Annotated by Barry R. Ashpole

The thought is that patients have difficulty accurately predicting their preferences for an uncertain future when confronted with unidentifiable conditions and unfamiliar treatments. A document written in the past may not best reflect what the patient now values or what would serve her best interests.

'When advance directives collide' (p.11), in *Journal of General Internal Medicine*.

## Canada

### Medical aid in dying not driven by lack of access to palliative care: New study

ONTARIO | The Canadian Press – 12 February 2020 – Medical aid in dying is not being driven by factors such as poverty, isolation, or lack of access to proper palliative care (PC), according to a new study by Canadian researchers.<sup>1</sup> The study dispels concerns that vulnerable people were being pushed into requesting medical aid in dying because they had few other options, says lead author James Downar, PC specialist at The Ottawa Hospital and the University of Ottawa. “When I look at his data ... it tells me that (medical aid in dying) is really not being driven by a lack of access of to PC,” Downar said in an interview. He added that the data also shows the procedure is not being driven by “socioeconomic vulnerability.” Medical aid in dying was legalized in Quebec in 2014 and then across Canada in June 2016. The study analyzed clinical and socioeconomic data from

2,241 Ontarians who received the procedure between June 2016 and October 2018. Researchers compared the data to those of 186,814 Ontario residents who died during the same time period. Downar said the study is the first of its scale to be conducted on medical aid in dying and benefited from Canadian data. He said he wasn't surprised by the results because studies in the U.S. and in Switzerland produced similar findings. <http://bit.ly/2uw1snh>

#### According to the Ontario study

Of the 2,241 people who chose to die with medical assistance in the Canadian province of Ontario between June 2016 and October 2018, 74% were receiving PC from a physician or nurse.

1. 'Early experience with medical assistance in dying in Ontario, Canada: A cohort study,' *Canadian Medical Association Journal*, published online 11 February 2020. **Abstract:** <http://bit.ly/2He8P5s>

Cont.

## Related:

- EXPERT ADVISORY GROUP ON MEDICAL ASSISTANCE IN DYING | Online – 13 February 2020 – **‘Canada at a Crossroads: Recommendations on Medical Assistance in Dying and Persons with a Mental Disorder.’** Following a comprehensive review of the available evidence, the Expert Advisory Group (EAG) has released a report cautioning that evolving assisted dying policies must not put the lives of Canadian who live with mental illness at risk. Medical assistance in dying is for medical conditions with irreversible decline, yet unlike other medical conditions mental illnesses can never be predicted to be irreversible. The EAG report highlights the need to set evidence-based policies and not discriminatorily ignore the realities of mental illness. **Download/view at:** <http://bit.ly/31WoDU3>

## Ottawa paramedics to get new powers to treat palliative patients at home

ONTARIO | *The Ottawa Citizen* – 10 February 2020 – A one-year pilot project is part of the provincial government’s push to keep people out of crowded hospitals and in their own homes when possible. The pilot would take some pressure off hospital emergency departments. Currently, under provincial law, paramedics are required to take palliative care patients in need of pain or symptom relief who call 911 to an emergency department for treatment. The pilot allows eligible patients to have the option of being treated at home after calling 911. The province’s Ambulance Act and Health Insurance Act will be amended to allow for the change. Ottawa paramedics will receive special training to assess the patient’s condition when they arrive. They will be able to administer medication for pain relief, shortness of breath, hallucinations, agitation, nausea, vomiting and congested breathing. <http://bit.ly/2Sw6l25>

**N.B.** Additional articles on the role of paramedics in palliative care noted in 20 January 2020 issue of Media Watch (#649, p.9).

## U.S.A.

### Congress to tackle hospice quality in new legislation

*HOSPICE NEWS* | Online – 10 February 2020 – Bipartisan legislation is designed to strengthen regulatory oversight of hospice providers in the wake of two July 2019 reports from the U.S. Department of Health & Human Services Office of Inspector General (OIG).<sup>1,2</sup> The reports garnered widespread media attention and elicited strong reactions from hospice organizations. In addition to bringing attention to safety incidents in hospices, the reports called into question the effectiveness of the U.S. Centers for Medicare & Medicaid Services’ (CMS) enforcement strategies. The HOSPICE Act is designed to bring hospice oversight in line with that of other post-acute care settings by providing the U.S. Department of Health & Human Services with new powers to oversee and penalize hospices that found to have serious quality deficiencies, develop more stringent CMS and state agency surveys, and improve surveyor training, as well as increase transparency for patients and families, including a requirement that states establish toll-free hotlines through which families could report abuse or neglect. <http://bit.ly/2HgUfu2>

### Specialist Publications

**‘Racial and ethnic disparity in palliative care and hospice use’** (p.5), in *American Journal of Managed Care*.

**‘Strategies to optimize the use of compassionate release from U.S. prisons’** (p.6), in *American Journal of Public Health*.

**‘State of palliative care services at U.S. cancer centers: An updated national survey’** (p.9), in *Cancer*.

**‘Content analysis of negative online reviews of hospice agencies in the U.S.’** (p.9), in *JAMA Network Open*.

**‘Differences in caregiver reports of the quality of hospice care across settings’** (p.10), in *Journal of the American Geriatrics Society*.

**‘Estimates of medication diversion in hospice’** (p.10), in *Journal of the American Medical Association*.

Cont.

1. 'Hospice Deficiencies Pose Risk for Medicare Beneficiaries,' Office of the Inspector General, Department of Health & Human Services, July 2019. [Noted in 15 July 2019 issue of Media Watch (#622, p.2)] **Download/view at:** <http://bit.ly/2XTBPJH>
2. 'Vulnerabilities in Hospice Care,' Office of the Inspector General, Department of Health & Human Services, July 2019. [Noted in 15 July 2019 issue of Media Watch (#622, p.2)] **Download/view at:** <http://bit.ly/2Jw6inO>

## Ohio allows hospices to provide inpatient palliative care

OHIO | *Hospice News* – 11 February 2020 – New rules in the state of Ohio will allow hospices to admit non-hospice palliative care (PC) patients into their inpatient facilities on a short-term basis when medically necessary. About half of the community-based PC providers in the U.S. are hospices, according to recent research from the Center to Advance Palliative Care (CAPC).<sup>1</sup> CAPC developed an online survey to which 890 PC providers responded. Ohio has also revised its statutory definition for PC: PC is “specialized care for patients of any age with a serious or life-threatening illness that is provided at any stage of the illness by an interdisciplinary team, including those seeking to cure the illness, that aims to relieve symptoms of stress and suffering; improve the patient’s quality of life; address the patient’s physical, emotional, social and spiritual needs; and facilitate patient autonomy, access to information and medical decision-making,” according to a memorandum written by a health policy researcher with the Bureau of Regulatory Operations at the Ohio Department of Health. The policy change is pursuant to the state’s House Bill 286, which was passed in March 2019, with a 2020 implementation date. <http://bit.ly/2SDReJk>

1. 'Mapping community palliative care: A snapshot,' Center to Advance Palliative Care, New York City, New York, December 2019. [Noted in 23 December 2019 issue of Media Watch (#645, p.3)] **Download/view at:** <http://bit.ly/2tswrzB>

## International

### Public surveyed on how much they know about dying and death

AUSTRALIA (Tasmania) | *The Advocate* (Burnie) – 13 February 2020 – What do you know about death and dying? It’s a topic most people will do a lot to avoid, but there are quite a few people in the Central Coast and Waratah-Wynyard Council areas who have taken the plunge to test their knowledge. They are among the Cradle Coast residents who have answered a pilot survey on what they know about the death system in Tasmania. The survey is being run by the University of Western Sydney and The Wicking Trust, and it aims to find out the levels of so-called “death literacy” nationally and locally, and how effective community-based projects have been. <http://bit.ly/31QVSYJ>

### Catholic hospitals forcing palliative care on patients who request euthanasia

BELGIUM | *The Brussels Times* – 13 February 2020 – The so-called “palliative filter” is a concept that was first discussed at the time of the passage of Belgium’s euthanasia law in 2002, but ultimately rejected. Then it was supported by Catholic bishops among others as a means of hollowing out the right to euthanasia enshrined in the law. In practice, a terminally-ill patient who is admitted to a Catholic hospital

### Specialist Publications

**'The right of palliative care for the most vulnerable in Africa is everyone's responsibility'** (p.4), in *African Human Rights Law Journal*.

**'Provision of palliative and end-of-life care in New Zealand residential aged care facilities: General practitioners' perspectives'** (p.6), in *Australian Journal of Primary Care*.

**'End-of-life experience for older adults in Ireland: Results from the Irish longitudinal study on ageing'** (p.7), in *BMC Health Services Research*.

**'Deciding for when you can't decide: The Medical Treatment Planning & Decisions Act 2016 (Victoria, Australia)'** (p.11), in *Journal of Bioethical Inquiry*.

**'Can there be wrongful life at the end of life? German courts revisit an old problem in a new context'** (p.12), in *Journal of Medical Ethics*.

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and requests euthanasia – or in some cases who has already requested it and made the arrangements – will run up against the hospital's insistence on first undergoing a process of palliative care (PC). Since PC, almost by definition, only ends when the patient dies, that is often what happens, with the patient ultimately being deprived of their chosen end-of-life (EoL) arrangements. The basic principle behind the palliative filter is the belief that a request for euthanasia is not the expression of a desire for one's life to be brought actively to an end, but rather an expression of a need for help in making the EoL tolerable. <http://bit.ly/3bxZIE9>

### **New white paper: *Allied Health in Australia and its Role in Palliative Care***

AUSTRALIA | CareSearch (Flinders University, South Australia) – Accessed 11 February 2020 – Allied Health (AH) is a key part of palliative care (PC) provision but evidence about their role and practice is still emerging. As part of the CareSearch Engagement Project, a background paper on the context of AH practice in Australia was produced for use by professionals, services, and AH organisations. Key findings include the need to support AH with education and upskilling, funding to support their work in PC, and more accurate data on the use of AH services. **Download/view at:** <http://bit.ly/39tsn1U>

**N.B.** CareSearch Engagement Project website: <http://bit.ly/2w4ilAb>

### **Does current palliative and end of life care research match the priorities of patients, carers and clinicians? A grant mapping analysis of the U.K. Clinical Research Collaboration's Health Research Classification System dataset 2014**

U.K. | AMRC (Association of Medical Research Charities) Research Report – 11 February 2020 – This report highlights under-researched areas in palliative and end-of-life care. It provides a snapshot of ongoing and very recent research by mapping research activity in 2014 against 83 questions from patients, carers and health and social care professionals. The report is for researchers, funders and policy planners to: 1) Avoid duplication by highlighting current research; 2) Foster collaboration by showing who is already active in addressing specific research questions; and, 3) Identify and tackle questions that are not currently examined at all. **Abstract:** <http://bit.ly/2USk5fO>

**N.B.** Additional articles on priorities in palliative care noted in 10 February 2020 issue of Media Watch (#652, p.6).

## **Specialist Publications**

### **Paediatric palliative care**

#### **The right of palliative care for the most vulnerable in Africa is everyone's responsibility**

*AFRICAN HUMAN RIGHTS LAW JOURNAL*, 2019;19(2):653-674. In sub-Saharan Africa over 80% of needy children are unable to access palliative care (PC) services. Since the introduction of the Convention on the Rights of the Child and the African Charter on the Rights & Welfare of Children, the three countries selected for this study, South Africa, Uganda and Kenya, have committed themselves to protect and promote the rights of children. Within the broader framework of international human rights, countries are obligated to realise a child's right to health and provide adequate health care. Yet, children living in these countries with life-threatening and life-limiting illnesses suffer from physical, psychological and emotional pain. The objective of the article is to focus on the plight of seriously ill children in sub-Saharan Africa. This includes highlighting their basic human right to paediatric PC and the challenges they encounter in receiving the necessary help. In examining a right to health it is understood that encapsulated within that right is the availability and access to PC for all who require such care. It is important for states to understand that realising universal health coverage is not possible unless existing legislative and social barriers, inadequate healthcare services and training of healthcare providers are addressed. In order to im-

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prove the monitoring and evaluation of needs and services, and remove the social, political and economic barriers, state involvement is necessary. The primary argument is that it is possible to successfully implement PC even in circumstances where resources are limited. The approach adopted calls for an increased understanding and the buy-in of representatives of government, civil society ... and affected communities all working toward a common agenda and effectively utilising existing community resources. **Full text:** <http://bit.ly/2UNxy pb>

### Racial and ethnic disparity in palliative care and hospice use

*AMERICAN JOURNAL OF MANAGED CARE* | Online – 11 February 2020 – Prior research has demonstrated differences across race and ethnicity, as well as across geographic location, in palliative care (PC) and hospice use for patients near the end of life (EoL). However, there remains inconsistent evidence regarding whether these disparities are explained by hospital-level practice variation. The goals of this study were to evaluate whether inpatient PC consultation use and discharge to hospice differed by race/ethnicity and whether hospital-level variations explained these differences. This study evaluated 5,613 patients who were discharged to hospice or died during their hospital stay between 2012 and 2014 in 4 urban hospitals with an inpatient PC service. The main outcomes were receipt of an inpatient PC consultation and discharge to hospice. The sample was 43% white, 44% African American, and 13% Hispanic. After adjusting for patient characteristics and hospital site, race/ethnicity was not significantly associated with receipt of inpatient PC consultation. Hispanic race/ethnicity was associated with a higher likelihood of discharge to hospice, and inpatient PC consultation was associated with 4 times higher likelihood of discharge to hospice. Hospital site was also associated with both receipt of inpatient PC consultation and discharge to hospice. The results of this study illustrate significant variation across hospitals in PC consultation use and discharge to hospice. No significant racial/ethnic disparities in the use of either PC or hospice at the EoL were found within hospitals. **Full text:** <http://bit.ly/3bCBDCL>

**N.B.** Additional articles on ethnic and racial disparities in the provision and delivery of palliative and end-of-life care in the U.S. noted in 9 September 2019 issue of Media Watch (#630, p.7).



#### [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>



#### Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.19.



Back Issues of Media Watch  
<http://bit.ly/2ThijkC>

## Strategies to optimize the use of compassionate release from U.S. prisons

*AMERICAN JOURNAL OF PUBLIC HEALTH*, 2020;110(S1):S25-S26. Adults aged 50 years or older constituted 10% of the U.S. prison population in 2012 and 20% in 2017. Many factors have contributed to the aging of the prison population, including reduced judicial discretion (e.g., mandatory minimum sentences, “three strikes” legislation), indeterminate sentencing, and the reintroduction of life without parole. As many incarcerated older adults experience multiple physical and mental health conditions at higher rates than do non-incarcerated persons, prison yards are now peppered with walkers, wheelchairs, and other durable medical equipment. Incarcerated older adults are also vulnerable to predation and often live in environments not designed to meet their physical needs. As a result, older adults generate high costs for overcrowded correctional systems, many of which are ill suited to provide the complex medical care needed for patients of advanced age or approaching the end of life (EoL). In response to the aging of the prison population, many jurisdictions have introduced or reinvigorated legal mechanisms to release or parole people with life-limiting illness early to their communities. Nearly all states have some form of early release policies, including medical parole, medical release, and “geriatric” parole ... (all herein referred to as “compassionate release”). Such mechanisms are critical release valves for bloated U.S. correctional facilities and can serve as supportive, human rights-oriented strategies for unifying families at the EoL and transferring persons to community-based healthcare systems that are better equipped to meet their complex health needs. **Full text:** <http://bit.ly/2ScUqNe>

### Extracts from *American Journal of Public Health* article

Fear of litigation may also permeate conversations about life-limiting illness and release, as some clinicians worry about the legal consequences of releasing a person who lives beyond the expected time-frame.

Lack of knowledge about serious and terminal illness among parole board members can also pose a barrier if the board does not possess sufficient medical knowledge to understand the trajectory of serious illness.



Prison Hospice: Backgrounder

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

Photo: Lori Waselchuk. Philadelphia, PA

## Provision of palliative and end-of-life care in New Zealand residential aged care facilities: General practitioners' perspectives

*AUSTRALIAN JOURNAL OF PRIMARY CARE* | Online – 14 February 2020 – This exploratory study examined general practitioners' (GPs) perspectives on delivering end-of-life care (EoLC) in the New Zealand residential aged care context. Findings examine: 1) GPs' life experience; 2) The GP relationship with the facilities and provision of EoLC; 3) The GP interaction with families of dying residents; and, 4) GP Relationship with hospice. The nature of the GP relationship with the facility influenced GP involvement in EoLC in aged care facilities, with GPs not always able to direct a facility's EoLC decisions for specific residents. GP participation in EoLC was constrained by GP time availability and the costs to the facilities for that time. GPs reported seldom using hospice services for residents, but did use the reputation (cachet) associated with hospice practices to provide an authoritative buffer for their end-of-life clinical decisions when talking with families and residents. GP training in EoLC, especially for those with dementia, was reported as *ad hoc* and done through informal mentoring between GPs. **Abstract (w. list of references):** <http://bit.ly/2OT1e09>

## End-of-life experience for older adults in Ireland: Results from the Irish longitudinal study on ageing

*BMC HEALTH SERVICES RESEARCH* | Online – 14 February 2020 – Ireland is ranked among the leading countries for end-of-life care provision yet significant gaps and difficulties in experience for older people are observable. People with cancer are more likely to die at home or in hospice, contrary to policies recommending palliative care as a component of all serious chronic disease management. High proportion of hospital deaths, including strong association with living alone and diseases other than cancer, indicates inadequate community and home care supports. Unpaid informal care accounts for 37% of all care received but access to this care, as well as important outcomes, may be adversely affected by living alone or in a rural area. Further consideration of policies to support unpaid carers, is warranted. **Full text:** <http://bit.ly/2SvtiJf>

Noted in Media Watch 10 February 2020 (#652, p.7):

- *HRB OPEN RESEARCH* | Online – 3 December 2019 – ‘**Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?**’ The number of people in Ireland dying from a disease associated with palliative care (PC) need is estimated to increase 68% between 2016 and 2046 if levels of need stay constant. Under assumptions of changing need, increases are estimated in the range 78-84% depending on projection method employed. The equivalent estimates for England & Wales between 2015 and 2040 are 25% with constant needs and up to 47% with changing needs.<sup>1</sup> The number of people living with a disease associated with PC need outnumber those in the last year of life with a relevant diagnosis by 12:1... **Full text:** <http://bit.ly/2OzrhJJ>

1. ‘How many people will need palliative care in 2040? Past trends, future projections and implications for services,’ *BMC Medicine*, published online 18 May 2017. [Noted in 22 May 2017 issue of Media Watch (#513, p.11)] **Full text:** <http://bit.ly/2IHcYCi>

## Identification of patients in need of general and specialised PALLiative care (ID-PALL<sup>®</sup>): Item generation, content and face validity of a new interprofessional screening instrument

*BMC PALLIATIVE CARE* | Online – 12 February 2020 – The results of this study represent the first step of the validation process of the newly developed ID-PALL<sup>®</sup> instrument. The methods used in the development have resulted in an instrument that is brief and tailored to the needs of all health professionals, nurses in particular, who are confronted with patients with a potential need for palliative care (PC). This instrument should allow the distinction between patients requiring general vs. specialised PC, regardless of their pathology. The authors are currently analysing the criterion validity of this instrument in order to assess its sensitivity and the specificity compared with the evaluation of a specialised interprofessional PC team including both nurses and physicians. An implementation study is currently being designed for the wider implementation of this instrument into clinical practice. **Full text:** <http://bit.ly/2SHSPrg>

### Related:

- *BMC PALLIATIVE CARE* | Online – 10 February 2020 – ‘**Who needs and continues to need paediatric palliative care? An evaluation of utility and feasibility of the Paediatric Palliative Screening Scale (PaPaS).**’ The PaPaS promotes greater clarity and effective handover for everyone involved, particularly at care transitions. This can lead to important outcomes like alignment of expectations between stakeholders, and critically, optimal case management. Ultimately, the child and family living with life-shortening illness is flagged in a timely manner to receive PC based on needs rather than prognosis, in spite of challenges posed by disease diversity and uncertain trajectories, through a process of screening that is both robust and informational... **Full text:** <http://bit.ly/2UHdk0f>



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## Managing do not attempt cardiopulmonary resuscitation conversations in the community

*BRITISH JOURNAL OF COMMUNITY NURSING* | Online – 10 February 2020 – Do not attempt cardiopulmonary resuscitation (DNACPR) conversations can help patients accept their impending death and achieve a more dignified death. This research explored the experiences and communication strategies of clinical nurse specialists (CNSs) in palliative care (PC) when managing DNACPR conversations in the community. Delays in end-of-life discussions mean that some community PC CNSs are having DNACPR conversations at their first meeting with patients. Balancing being clear and sensitive is challenging, especially when patients and families have previously been informed inappropriately or insensitively about DNACPR decisions. Discussions should be initiated by exploring patient understanding and preferences while emphasising care continuation and a more dignified death. **Abstract:** <http://bit.ly/31ORycE>

## GPs' role in caring for children and young people with life-limiting conditions: A retrospective cohort study

*BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 10 February 2020 – Children with life-limiting conditions (LLCs) are high users of healthcare. GPs have a key role in the management of patients with LLCs and complexity, including children. However, children's healthcare is often specialist led and GPs are less involved. Primary care studies in adult populations demonstrate the value of continuity of care. This has been compromised by changes in the organisation of GP services, including out-of-hours provision and GP contracting. This study suggests that the consistent and regular involvement of a GP in the care of children with an LLC is associated with reduced emergency secondary care use. This is the first study of its type to examine the potential impact of regular GP attendance and continuity of care with a GP for paediatric patients with LLCs. **Full text:** <http://bit.ly/2HomGpL>

## Can patients use family members as non-professional interpreters in consultations?

*BRITISH MEDICAL JOURNAL* | Online – 11 February 2020 – Sofia Sarfraz, senior clinical fellow in paediatrics and medical education, says: "For patients who don't share your language the gold standard is to use a professional interpreter. We've all, however, used patients' family members or other health professionals as interpreters in consultations. It's hard to see how medicine could function in our multicultural society without them, especially in emergencies. But non-professional interpreters should be used with caution and you should consider the risks. Medical interpreters have training and experience, which family members and other health professionals may lack. Interpreters should be neutral and passive, which may prove difficult for family. A family member may also give you their own version of events, and their emphasis may skew the whole consultation. It can also be difficult to check the veracity of the interpretation. This could lead to a misdiagnosis. Similarly, a family member may find it hard to share difficult or bad news and they may have emotional or cultural reasons to distort your message. Or they may simply be bashful. Be aware that over-reliance on minors as translators can cause them harm. This can range from the child being taken out of school to act as an interpreter, to being traumatised by their exposure to a complex medical communication scenario. A final point to consider is that using interpreters can alter the dynamic of the consultation and failing to recognise this can degrade the quality of care." **Full text:** <http://bit.ly/2SzE401>

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

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 3 April 2017 – '**Understanding patient needs without understanding the patient: The need for complementary use of professional interpreters in end-of-life care.**' In linguistically and culturally diverse societies, language discordant consultations become daily practice, leading to difficulties in eliciting patient preferences toward end-of-life care. The case discussed generated a triple-layered ethical dilemma: 1) How to safeguard patient autonomy against paternalistic interventions by family members; 2) How to respect the relational context in which patient autonomy can be realized; and, 3) How to respect the ethno-cultural values of the patient and his family. **Abstract (w. list of references):** <http://bit.ly/2JqsyjL>

## **State of palliative care services at U.S. cancer centers: An updated national survey**

*CANCER* | Online – 12 February 2020 – Between April and August 2018, all National Cancer Institute (NCI)-designated cancer centers and a random sample of 1,252 non-NCI-designated cancer centers were surveyed. Survey findings from 2018 were compared with 2009 data from 101 cancer center executives and 96 palliative care (PC) program leaders. Among NCI-designated cancer centers, a significant increase in outpatient PC clinics was observed between 2009 and 2018 with no significant changes in inpatient consultation teams, PC units, or institution-operated hospices. Among non-NCI-designated cancer centers, there was no significant increase in outpatient PC clinics, inpatient consultation teams, PCUs, or institution-operated hospices. The median interval from outpatient PC referral to death increased significantly, particularly for NCI-designated cancer centers. Despite significant growth in outpatient PC clinics, there remain opportunities for improvement in the structures and processes of PC programs. **Abstract:** <http://bit.ly/2SuB4U1>

## **Evolving definitions of palliative care: Upstream migration or confusion?**

*CURRENT TREATMENT OPTIONS IN ONCOLOGY* | Online – 11 February 2020 – Palliative care (PC) has evolved over the decades from its roots in the hospice movement to a much wider approach in which early intervention further “upstream” in the illness is encouraged to improve quality of life for patients and their families. This new definition has a strong evidence base in cancer trials and is supported by major national and international organizations. However, it has proven difficult to convince patients, the public, and even healthcare providers, of this upstream migration of PC, with many continuing to associate PC exclusively with end-of-life care (EoLC). A multitude of definitions now exists, with varying emphasis on early intervention versus EoLC. In addition, a new nomenclature has emerged to conceal the end-of-life component of PC despite its continued importance, adding further to the confusion. Uncertainty within the specialty about the definition of PC will not reassure referring physicians and policymakers about its meaning nor convince them of its importance. Accuracy and clarity in the form of an established definition of PC are required to reduce misconceptions, facilitate clinical and academic development, and promote effective communication. This definition should acknowledge both expertise in EoLC and its relevance for improving outcomes early in the course of advanced cancer, and should be disseminated widely and practiced consistently. **Abstract:** <http://bit.ly/2OSWQ1m>

## **Content analysis of negative online reviews of hospice agencies in the U.S.**

*JAMA NETWORK OPEN* | Online 12 February 2020 – As online reviews of healthcare become increasingly integral to patient decision-making, understanding their content can help healthcare practices identify and address patient concerns. Of 100 hospice agencies in the study sample, 67 (67.0%) had 1-star reviews; 33 (49.3%) were for-profit facilities and 34 (50.7%) were non-profit facilities. Of 137 unique reviews, 68 (49.6%) were for for-profit facilities and 69 (50.4%) were for non-profit facilities. Five themes emerged: 1) Discordant expectations; 2) Suboptimal communication; 3) Quality of care; 4) Misperceptions about the role of hospice; and, 5) The meaning of a good death. The first 3 themes were categorized as actionable criticisms, which are variables hospice organizations could change. The remaining 2 themes were categorized as unactionable criticisms, which are factors that would require larger systematic changes to address. For both for-profit and non-profit hospice agencies, quality of care was the most frequently commented-on theme. For-profit hospice agencies received more communication-related comments overall, while non-profit hospice agencies received more comments about the role of hospice and the quality of death. Regarding actionable criticisms, hospice agencies could examine their current practices, given that reviewers described these issues as negatively affecting the already difficult experience of losing a loved one. The findings indicated that patients and their families, friends, and caregivers require in-depth instruction and guidance on what they can expect from hospice staff, hospice services, and the dying process. Several criticisms identified in this study may be mitigated through operationalized, explicit conversations about these topics during hospice enrollment. **Full text:** <http://bit.ly/38tia5p>

**Related:**

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 10 February 2020 – ‘**Differences in caregiver reports of the quality of hospice care across settings.**’ Seven quality measures are identified, including five composite measures that assess aspects of hospice care important to patients and families, including hospice team communication, timeliness of care, treating family member with respect, symptom management, and emotional and spiritual support, and two global measures of the overall rating of the hospice and willingness to recommend it to friends and family. Hospice team communication, treating family member with respect, and providing emotional and spiritual support were most strongly associated with overall rating of care. **Abstract:** <http://bit.ly/37bv8TF>

**Comparison of integrated outpatient palliative care with standard care in patients with Parkinson’s disease and related disorders: A randomized clinical trial**

*JAMA NEUROLOGY* | Online – 10 February 2020 – The integration of palliative care (PC) into Parkinson’s disease and related disorders (PDRD) care holds the potential to improve outcomes, particularly for persons who are underserved by current models of care (e.g., patients with advanced illness and dementia). As a new application of PC, a need exists to optimize the intervention, particularly for caregivers, and to develop models appropriate for implementation in non-academic settings and among diverse populations. Because the PC intervention is time and resource intensive, future studies should optimize triage tools and consider alternative models of care delivery, such as telemedicine or care navigators, to provide key aspects of the intervention at lower cost. Despite these limitations, the study’s results provide a starting point for future studies integrating PC into standard care for patients with PDRD and other chronic illnesses. **Full text:** <http://bit.ly/2Sde7o6>

**Palliative programs for persons with Parkinsonism: The next frontier**

*JAMA NEUROLOGY* | Online – 10 February 2020 – In current practice, palliative care (PC) is either not introduced at all to persons with Parkinson’s disease (PD), or it is introduced very late, in the final disease stages before death. This reluctance to consider PC likely exists because PD is generally not conceptualized as a terminal illness because of its slowly progressive nature and typically long survival. However, another explanation relates to scientific underpinning; we do not fully understand which components of palliation are useful for persons with PD, in which disease phase these palliations should be applied, and how to implement PC for this population. **Abstract:** <http://bit.ly/37evjO3>

**N.B.** Additional articles on PC for patients living with PD noted in 16 September 2019 issue of Media Watch (#631, pp.6-7).

**Estimates of medication diversion in hospice [in the U.S.]**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2020;323(6):566-568. Given the challenges of symptom management during hospice care, patients require responsive opioid prescribing. Within the context of the national opioid crisis, medication diversion in hospice is an increasing concern. The authors conducted a national survey of hospices (June-September 2018). Using 2015 data on U.S. hospices, they randomly selected 600 agencies, proportionately stratified by state and profit status. The authors surveyed agency representatives by phone or online about practices, policies, and experiences regarding medication diversion. **Abstract:** <http://bit.ly/2uAETxu>

**N.B.** Additional articles on medication diversion in the hospice in the U.S. noted in 13 January 2020 (#648, p.5).



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

## **Deciding for when you can't decide: The Medical Treatment Planning & Decisions Act 2016 (Victoria, Australia)**

*JOURNAL OF BIOETHICAL INQUIRY* | Online – 13 February 2020 – The Australian state of Victoria introduced new legislation regulating medical treatment and associated decision-making in March 2018. In this article, the authors provide an overview of the new Medical Treatment Planning & Decisions Act 2016 (Vic) and compare it to the former (now repealed) Medical Treatment Act 1988. Most substantially, the new Act provides for persons with relevant decision-making capacity to make decisions in advance regarding their potential future medical care, to take effect in the event they themselves do not have decision-making capacity. Prima facie, the new Act enshrines autonomy as the pre-eminent value underlying the state's approach to medical treatment decision-making and associated surrogate decision-making. However, we contend that the intention of the Act may not accord with implementation of the Act to date if members of the community are not aware of the Act's provisions or are not engaged in advance care planning. There is a need for further research, robust community advocacy, and wider engagement for the intention of the Act – the promotion of “precedent autonomy” in respect to surrogate medical treatment decision-making – to be fully realized. **Abstract (w. list of references):** <http://bit.ly/37t8Vkf>

### **Review of U.S. state laws**

#### **When advance directives collide**

*JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 4 February 2020 – What happens when the healthcare power of attorney's decision conflicts with the patient's living will (LW) regarding end-of-life treatment? That is – what happens when the designated person serving as the Healthcare Power of Attorney (HcPOA) refuses to follow the patient's treatment preferences documented in the LW? States and territories treat this issue differently. Ohio law ... mandates that the LW takes precedence over the HcPOA when in conflict, which is even explicitly stated in the standard Ohio advance directive form. Other states, like Maryland and North Carolina, grant patients the power to dictate whether their treatment preferences documented in the LW are to be followed strictly or if they merely serve as guidance that can be overridden by a HcPOA. The laws of many states, like Arizona, Connecticut, and Minnesota, are silent on this matter. In Georgia, however, state law ... dictates that when a HcPOA and a LW exist simultaneously and conflict with each other, the HcPOA takes precedence over the LW, specifically regarding any directives about withholding or withdrawing life-sustaining treatments; HcPOAs do have the duty to make decisions that are “consistent with the intentions and desires of the patient,” to enforce this duty on a wayward HcPOA requires an interested party to petition the local courts to remove the HcPOA's decision-making authority, a time-intensive and inefficient process. **Full text:** <http://bit.ly/387Dey5>

Noted in Media Watch 10 July 2017 (#520, p.3):

- *HEALTH AFFAIRS*, 2017;36(7):1244-1251. ‘**Approximately one in three U.S. adults completes any type of advance directive for end-of-life care.**’ The authors systematically reviewed studies published in the period 2011-2016 to determine the proportion of U.S. adults with a completed living will, healthcare power of attorney, or both. Among the 795,909 people in the 150 studies analyzed, 36.7% had completed an advance directive (AD), including 29.3% with living wills. These proportions were similar across the years reviewed. Similar proportions of patients with chronic illnesses (38.2%) and healthy adults (32.7%) had completed ADs. The findings provide benchmarks for gauging future policies and practices designed to motivate completion of ADs... **Abstract:** <http://bit.ly/2v17Z4g>

#### **Consequences of “conversations not had”: Insights into failures in communication affecting delays in hospital discharge for older people living with frailty**

*JOURNAL OF HEALTH SERVICES RESEARCH & POLICY* | Online – 3 February 2020 – Some of the authors' findings reflect well-known barriers to hospital discharge including service fragmentation, requiring skilled coordination that was often not available due to high volumes of work, and poor communication between staff from different organizations. Study participants' accounts also referred to less frequently

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documented factors that affect decision-making and the organization of patient discharges. These raised uncomfortable emotions and tensions that were often ignored or avoided. One participant referred to “conversations not had,” or failures in communication, because difficult topics about resuscitation, escalation of treatment and end-of-life (EoL) care for older people living with frailty (OPLWF) were not addressed. The consequences of not initiating important conversations about decisions relating to the EoL are potentially far reaching not only regarding reduced efficiency due to delayed discharges but also for patients’ quality of life and care. As the population of older people is rising, this becomes a key priority for all practitioners in health and social care. Evidence to support practitioners, OPLWF and their families is needed to ensure that these vital conversations take place so that care at the EoL is humane and compassionate. **Abstract (w. list of references):** <http://bit.ly/2S9PKHR>

Noted in Media Watch 18 November 2019 (#640, p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 15 November 2019 – ‘**End-of-life care for frail older people.**’ Geriatricians use a model called comprehensive geriatric assessment, including medical, functional, mental health, social and environmental dimensions, but they also use a variety of other models, such as the acute medical model, person-centred care, rehabilitation, alongside palliative care (PC). Features such as communication, family engagement and advance planning are common to them all. These approaches are often consistent with each other, but their commonalities are not always recognised. PC should be integrated with all medical care for frail older people. **Abstract:** <http://bit.ly/2XiskAS>

Noted in Media Watch 25 February 2019 (#603, p.13):

- *PALLIATIVE MEDICINE* | Online – 18 February 2019 – ‘**What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis.**’ Thirteen different measures or definitions of frailty were used. People with frailty experience pain and emotional distress at levels similar to people with cancer and also report a range of physical and psychosocial needs, including weakness and anxiety. Functional support needs were high and were highest where people with frailty were cognitively impaired. Individuals with frailty often expressed a preference for reduced intervention, but these preferences were not always observed at critical phases of care. **Full text:** <http://bit.ly/2SaPIMz>

### **Can there be wrongful life at the end of life? German courts revisit an old problem in a new context**

*JOURNAL OF MEDICAL ETHICS* | Online – 14 February 2020 – This article discusses a recent ruling by the German Federal Court concerning medical professional liability due to potentially unlawful clinically assisted nutrition and hydration (CANH) at the end of life. This case raises important ethical and legal questions regarding a third person’s right to judge the value of another person’s life and the concept of “wrongful life.” In their brief report, the authors discuss the concepts of the “value of life” and wrongful life, which were evoked by the court, and how these concepts apply to the present case. They examine whether and to what extent value-of-life judgments can be avoided in medical decision-making. The wrongful-life concept is crucial to the understanding of this case. It deals with the question whether life, even when suffering is involved, could ever be worse than death. The effects of this ruling on medical and legal practice in Germany are to be seen. It seems likely that it will discourage claims for compensation following life-sustaining treatment (LST). However, it is unclear to what extent physicians’ decisions will be affected, especially those concerning withdrawal of CANH. The authors conclude that there is a risk that LST may come to be seen as the “safe” option for the physician, and hence, as always appropriate. **Abstract:** <http://bit.ly/2OXtAGF>



Would this article be of interest to a colleague?

## Triggered palliative care consults: A systematic review of interventions for hospitalized and emergency department patients

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 12 February 2020 – Triggered palliative care consults (PCC) offer one way to identify patients who would benefit from palliative care (PC) and to connect them with services early in their course. Consensus reports recommend use of triggers to identify patients for PC consults, but no standards exist to guide trigger design or implementation. Twenty studies were included for final analysis with over 17,000 patients represented. Trigger processes and composition were heterogeneous, although frequently utilized categories such as cancer, dementia, and chronic comorbidities were identified. Three quarters of the studies were deemed to have moderate or high risk of bias. The authors present a range of trigger tools spanning different hospital settings and patient populations. Common themes in implementation and content arose but the limitations of these studies are notable and further rigorous randomized comparisons are needed to generate standards of care. Additionally, future studies should focus on developing triggers that identify patients requiring primary versus specialty level palliative care. **Abstract (w. link to references):** <http://bit.ly/37tdKk>

Noted in Media Watch 9 December 2019 (#643, p.17):

- *SUPPORTIVE CARE IN CANCER* | Online – 2 December 2019 – “**Triggers**” for early palliative care referral in patients with cancer: A review of urgent unplanned admissions and outcomes.’ Many triggers have been proposed, but are not commonly used. This study reviewed the timing of palliative care (PC) involvement for patients in a tertiary referral oncology hospital, and whether the use of a trigger tool prior to admission would have facilitated earlier referral. A total of 159 patients were identified. Forty-six percent were referred to PC prior to terminal admission. Application of 6 out of 7 trigger tools would have resulted in the majority of patients referred to PC prior to admission; 52.2%) were referred only during their terminal admission. **Abstract (w. list of references):** <http://bit.ly/34GKMGp>

## Looking back, and ahead: A call to action for increasing the hospice and palliative medicine specialty pipeline

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 February 2020 – Thanks to the efforts of many individuals and organizations, the field of hospice and palliative medicine (HPM) has undergone unprecedented growth over the last two decades. To meet the needs of seriously ill patients and families in inpatient, outpatient community setting in the future, the field of HPM must develop innovative strategies to expand the specialist workforce pipeline. With 148 programs participating in the National Residency Matching Program and 285 matched applicants in 2019, the specialty of HPM can barely replace those who are retiring or leaving the field. The authors call for a renewed and coordinated effort to increase the applicant pool for HPM fellowship positions, as well as greater access to specialist HPM training through expanded traditional fellowship programs and innovative specialist training pathways. Without such an expansion, our specialty will struggle to serve those patients and families who need us most. **Abstract:** <http://bit.ly/38qobj6>

Noted in Media Watch 23 September 2019 (#632, p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 16 September 2019 – ‘**Future-proofing the palliative care workforce: Why wait for the future?**’ Careful consideration of workforce issues is not new in palliative care (PC). Indeed, calls for workforce development and future workforce planning to address shortages have been evident within the international literature for quite some time. However, there now appears to be a growing urgency. Studies conducted by the American Academy of Hospice & Palliative Medicine’s Workforce Task Force have pointed towards an impending crises in the form of a “workforce valley” associated with factors such as burnout, intention to leave PC, retirement age demographics, and limitations in specialist training.<sup>1</sup> **First page view:** <http://bit.ly/2krYIC9>

1. ‘Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,’ *Health Affairs*, 2019;38(6):910-918. [Noted in 10 June 2019 issue of Media Watch (#617, p.1)] **Full text:** <http://bit.ly/2QMAU7N>

## “I’d want to know, because a year’s not a long time to prepare for a death”: Role of prognostic information in shared decision making among women with metastatic breast cancer

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 February 2020 – Effective shared decision making in metastatic breast cancer (MBC) treatment requires prognostic understanding, without which patients may receive treatment inconsistent with personal preferences. The authors conducted semi-structured interviews with MBC patients and community oncologists and separate focus groups involving lay navigators, nurses, and academic oncologists. Five emergent themes were identified. 1) Most patients wanted prognostic information but differed in when they wanted to have this conversation; 2) Emotional distress and discomfort was a critical reason for not discussing prognosis; 3) Religious beliefs shaped preferences for prognostic information; 4) Healthcare professionals differed on prognostic information delivery timing; and, 5) Providers acknowledged that an individualized approach taking into account patient values and preferences would be beneficial. Most MBC patients wanted prognostic information, yet varied in when they wanted this information. Understanding why patients want limited or unrestricted prognostic information can inform oncologists’ efforts toward shared decision making. **Abstract:** <http://bit.ly/31NxYx5>

## Insights from bereaved family members about end-of-life care and bereavement

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 February 2020 – Bereavement programs provide institutions with an avenue for obtaining feedback from family members about their experiences during a patient’s illness and end-of-life (EoL) period that can be used to improve both patient care and the care of bereaved individuals. The findings of this study showed that compassionate care, competency, receiving honest facts, and outreach after the death favorably influenced the bereavement experience. Conversely, impersonal contact, lack of contact, including lack of caregiver support, and lack of information about EoL and death were identified as actions taken by the clinical team that were unhelpful in dealing with their loss. The feedback from bereaved family members highlights two areas that could benefit from quality improvement efforts: 1) Communication skills that focus on enhancing compassionate connection, including conveying empathy, and providing reassur-

ance and guidance to patients and their families; and, 2) Communication skills that focus on delivering information about prognosis and the EoL period in an honest and direct way. **Abstract:** <http://bit.ly/2SfHWV2>

### The development and validation of the Meaning Making in Grief Scale

*DEATH STUDIES* | Online – 12 February 2020 – The research entailed three steps: 1) Scale development 2) Exploratory factor analysis; and, 3) Confirmatory factor analysis. The current 21-item scale was composed of three sub-scales: 1) Meaning of the significant other; 2) Being present; and, 3) Coping and growth. Support was found for the reliability and validity of the scale, as reflected in the high levels of coherence of the subscales and their hypothesized correlation with established measures of meaning and grief symptomatology. **Abstract:** <http://bit.ly/39rdwou>

Noted in Media Watch 4 November 2029 (#638, p.8):

- *BMC PALLIATIVE CARE* | Online 31 – October 2019 – ‘Dying in acute hospitals: Voices of bereaved relatives.’ This research provides a powerful snapshot in time into what works well and what could be improved in end-of-life care (EoLC) in acute hospitals. Findings are reported under several themes, including the overall quality of care, meeting care needs, communication, the hospital environment, and support for relatives. Improvements can be made that build on existing good practice that will enhance the experience of care for dying persons and their relatives. The study adds insights in relation to relative’s priorities for EoLC in acute hospitals and can advance care providers’, policy makers’ and educationalists’ priorities for service improvement. **Full text:** <http://bit.ly/324C42G>

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Noted in Media Watch 14 January 2019 (#597, p.17):

- *PALLIATIVE MEDICINE* | Online – 10 January 2019 – ‘**Assessing quality of care for the dying from the bereaved relatives’ perspective: Using pre-testing survey methods across seven countries to develop an international outcome measure.**’ Overall, the authors have developed a common, core international questionnaire (‘i-CODE’) with key questions pertaining to the quality of care for those who are dying. In addition, they have culturally adapted versions, combining the views of patient and public involvement representatives and, with the exception of Brazil, bereaved relatives’ views for each language. On an international basis, the i-CODE questionnaire appears to have good face and content validity. **Full text:** <http://bit.ly/2w8dvHA>

## Development of a new undergraduate palliative care knowledge measure

*JOURNAL OF PROFESSIONAL NURSING*, 2020;36(1):47-52. Knowledge of primary palliative care (PC) concepts is a fundamental expectation of graduating nursing students. The release of updated national educational competencies in PC [in the U.S.] coupled with a new PC curriculum for pre-licensure nursing students created a need to measure acquisition of new knowledge. The authors describe development and psychometric evaluation of a new PC measure. Development of the new measure was guided by an expert team of PC educators, incorporating existing knowledge measures as well as content from the newly developed curriculum. A 4-step process resulted in development of a 27-item measure reflecting the 17 new core competencies for undergraduate PC education. Initial pilot testing in a sample of 262 nursing students demonstrated good internal consistency, with a 2-factor model that aligns with multiple national expectations for primary PC. This study

is the first to align knowledge items with national PC competencies and care domains. Further psychometric testing will be conducted as well as large multisite research collaborations to test curriculum implementation and use this knowledge measure in pre-licensure nursing education. **Full text:** <http://bit.ly/2vqylMC>

### Making the most of a palliative care experience

*BRITISH MEDICAL JOURNAL* | Online – 11 February 2020 – At some point in their training, most medical students will encounter palliative care (PC) during their placements. In the U.K. nearly half of all deaths happen in hospital and therefore end-of-life (EoL) care is a core skill for junior doctors. This article outlines the importance and relevance of PC and offers advice on how to use a PC placement to optimise the future management of patients who are nearing the EoL. **Abstract:** <http://bit.ly/2ShiYo2>

### Related:

- *JOURNAL OF PROFESSIONAL NURSING*, 2020;36(1):42-46. ‘**Online palliative and end-of-life care education for undergraduate nurses.**’ The authors describe the development and delivery of an undergraduate-level online nursing elective course in palliative and end-of-life care offered through a large public university. Innovative elements of the course include practicing difficult conversations using technology to enable active student engagement in an online environment, a serious game involving individual role play for treatment decision making, and special topic weeks allowing a deeper dive into seldom discussed populations such as the homeless, which the students described as playing an important role in contributing to their learning. **Full text:** <http://bit.ly/2HhHr6l>

## “Give them the door but don’t push them through it”: Family attitudes toward physician-led spiritual care in pediatric palliative medicine

*JOURNAL OF RELIGION & HEALTH* | Online – 12 February 2020 – Little is known about pediatric caregivers’ perceptions of religious or spiritual (R/S) care provided by physicians. Three recurrent themes emerged [in this study] regarding physician-led R/S care: 1) Most caregivers view providing R/S care as a positive sign of physician empathy, while a minority prefer to keep R/S and medical care separate; 2) Many caregivers prefer R/S care from a physician with whom they have a close relationship and/or share a faith background; and, 3) Physicians should open the door, but allow families to lead conversations

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about R/S care. Caregivers have mixed perceptions on physicians engaging in R/S care; most prefer that families set the direction of R/S care for themselves and their loved ones. Physicians should be trained to evaluate families' spiritual backgrounds and needs in ways that respectfully open the door to these conversations. **Abstract:** <http://bit.ly/2Sqwlgn>

### **Hopelessness in palliative care for people with motor neurone disease: Conceptual considerations**

*NURSING ETHICS* | Online – 3 February 2020 – The concepts of hope and its absence, hopelessness, are seen as crucial in palliative care (PC) for people with motor neurone disease (MND). A primary measure in psychological research on hopelessness in people with MND is the Beck Hopelessness Scale. This scale can be understood as being conceptually based on the philosophical standard account of hope, which understands hope as an intentional expectancy. The author argues that this is a misconstruction of hopelessness in PC. Rather, pre-intentional hope is essential for PC of people with MND. Pre-intentional hope enables the formation of intentional hopes and is intrinsically relational. The absence of pre-intentional hope should not be subjected to psychiatric diagnosis, for example, in the form of demoralization disorder. **Abstract (w. list of references):** <http://bit.ly/2UIT1Qd>

**N.B.** Additional articles on PC for patients living with motor neurone disease noted in 15 July 2019 issue of *Media Watch* (/622, p.12).

### **Death narrative in 19th-Century China: How did newspapers frame death and dying**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 14 February 2020 – This study explored the death narrative in the late Qing dynasty as expressed in Chinese newspapers in the 19th century. Using textual analysis, this study identified three themes regarding death and dying during this period: euphemism of death, definition of “good death,” and Western influence on the death narrative. The study results of death narrative in the 19th century indicate the historical root of perception of death among the current Chinese people, which could help the development of a culturally sensitive hospice services for Chinese people in China and other countries by suggesting language use, patients approaching, and mental health intervention for the service providers and policy makers. **Abstract (w. list of references):** <http://bit.ly/3bw8mJE>

### **Comforting versus distressing dreams of the deceased: Relations to grief, trauma, attachment, continuing bonds, and post-dream reactions**

*OMEGA – JOURNAL OF DEATH & DYING* | Online – 9 February 2020 – Why are some dreams of the deceased experienced as comforting, while others are distressing? The authors propose that there are different types of dreams serving diverse functions. In particular, they considered three: processing trauma, maintaining a continuing bond, and regulating emotion. They also examined the impact of post-dream reactions on the bereaved's experience of their dreams. Participants were 216 individuals whose romantic partner or spouse had died. They provided reports of dreams of the deceased that were content analyzed and completed measures of grief intensity, post-traumatic symptoms, attachment style, internalized versus externalized continuing bonds, as well as questions about the death, and ratings of how they experienced the dream after awakening. Support was found for the three proposed functions, suggesting dreams of the deceased can actively facilitate adjustment to bereavement. In addition, there was evidence that post-dream reactions can impact both the perception of the dream and grief. **Abstract (w. list of references):** <http://bit.ly/31GSD5U>

### **Bio-politics in end-of-life care**

*REVISTA JURÍDICA DA PRESIDÊNCIA*, 2020;21(125):516-539. The authors discuss the important issue of how and when to decide a medical intervention is futile and a patient should be allowed to die. The problem is formulated around the agambenian concept of state of exception, in which no legislation will ever be sufficient to regulate these complex issues, exposing patients and physicians to an unchecked

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power over their lives. The Brazilian legislation exemplifies the unsolvability of the dilemma in modern Western societies, given law's impossibility to rigorously regulate every technical aspect of the ethical dilemma, as well as the technological discourse inability to face it on its own terms. The larger bio-political issue cannot be addressed with mere bioethical or legal solutions. Instead, it depends on our willingness to courageously confront multiple powers focused over our lives and deaths in the biotechnological society in which we live. Amidst multiple attacks from the bio-political apparatus, no more promises are needed. Instead, a permanent *memento mori* is more important, reminding us the limits of the human condition and the imprudence of the modern biotechnological promise, such that we strengthen our difficult resistance to those injunctions from a power that seemingly only wants our well-being (to make us live!). The alternative to this has grim implications in multiple scales. **Full text:** <http://bit.ly/2ODQGcf>

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

### **Association between strong patient-oncologist agreement regarding goals of care and aggressive care at end-of-life for patients with advanced cancer**

*SUPPORTIVE CARE IN CANCER* | Online – 14 February 2020 – The purpose of this study was to examine the influence of patient-oncologist agreement regarding goals of care upon aggressive care at end of life for patients with advanced cancer. Two hundred and six patients and eleven oncologists provided data. At the last interview prior to death, 23.3% of dyads had strong goal-of-care agreement for either survival (8.3%) or comfort (15%), and 76.7% had no strong agreement. There was a significant association between aggressive care use and categories of dyadic agreement regarding goals of care. A large percentage of oncologists did not understand their patients' EoL goals-of-care. While aggressive care aligned with categories of dyadic agreement for goals-of-care, high rates of aggressive care were reported. **Abstract (w. list of references):** <http://bit.ly/2SJLkGz>

## **Publishing Matters**

### **Defining predatory journals and responding to the threat they pose: A modified Delphi consensus process**

*BMJ OPEN* | Online – 9 February 2020 – Through snowball and purposive sampling of targeted experts, the authors identified 45 noted experts in predatory journals and journalology. The international group included funders, academics and representatives of academic institutions, librarians and information scientists, policy makers, journal editors, publishers, researchers involved in studying predatory journals and legitimate journals, and patient partners. In addition, 198 authors of articles discussing predatory journals were invited to participate... A total of 115 individuals ... completed the survey on predatory journals and publishers. The authors reached consensus on 18 items out of a total of 33 to be included in a consensus definition of predatory journals and publishers. They came to consensus on educational outreach and policy initiatives on which to focus, including the development of a single checklist to detect predatory journals and publishers, and public funding to support research in this general area. The authors identified technological solutions to address the problem: a “one-stop-shop” website to consolidate information on the topic and a “predatory journal research observatory” to identify ongoing research and analysis about predatory journals/publishers. In bringing together an international group of diverse stakeholders, the authors were able to use a modified Delphi process to inform the development of a definition of predatory journals and publishers. This definition will help institutions, funders and other stakeholders generate practical guidance on avoiding predatory journals and publishers. **Full text:** <http://bit.ly/2SdQaNr>



### **Centre for Journalology**

**N.B.** Centre for Journalology: <http://bit.ly/36Hxw5B>

## **A disclosure form for work submitted to medical journals: A proposal from the International Committee of Medical Journal Editors**

*NEW ENGLAND JOURNAL OF MEDICINE*, 2020; 382(7):667-668. Many factors, including professional and personal relationships and activities, can influence the design, conduct, and reporting of the clinical science that informs health care decision. The potential for conflict of interest exists when these relationships and activities may bias judgement. Many stakeholders – editors, peer reviewers, clinicians, educators, policymakers, patients, and the public – rely on the disclosure of authors' relationships and activities to inform their assessments. Trust in the transparency, consistency, and completeness of these disclosures is essential. Ten years ago, the International Committee of Medical Journal Editors (ICMJE) adopted the 'ICMJE Form for the Disclosure of Potential Conflicts of Interest' as a uniform mechanism for collecting and reporting authors' relationships and activities that readers might consider relevant to a published work. The goal was to avoid the confusion (and often ensuing controversy) created when journals vary in how they collect and report this information. **Full text:** <http://bit.ly/2uKg0Q7>



### **Media Watch: Editorial Practice**

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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 'e-Library' ('From Around the Region') and 'Media Watch Barry Ashpole']

### **Australia**

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

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### **Europe**



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTP://BIT.LY/300WMRT>

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

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

### **South America**

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

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