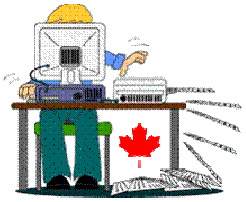
Media Watch...

*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.*

11 March 2019 Edition | Issue #605



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Compiled & Annotated by Barry R. Ashpole

'A scale to assess religious beliefs in end-of-life medical care' (p.8), in *Cancer*.

Canada

Better understanding of home care needed, says New Brunswick Health Council

NEW BRUNSWICK | Global TV News (St. John) – 5 March 2019 – The New Brunswick Health Council (NBHC) is hoping to shed light on why satisfaction of home care services varies across the province. New findings from the Council show that gaps exist in home care satisfaction across the province.[1] Stéphane Robichaud, chief executive of the NBHC, says it's not simply a matter of rural versus urban communities. According to Robichaud, fingers are often pointed at a lack of resources, but that isn't necessarily the case. "We also look at resource levels – how they compare across the province, how New Brunswick compares to Canada," he explained. Survey results from over 6,900 home care clients show overall satisfaction with services, but Robichaud says there's more to it. "These numbers do not give us the whole picture," he said. "Home care managers need to get much better at setting targets so that we can appreciate, 'Are we improving? Are we going in the right direction?" When asked about client satisfaction regarding the number of times a client receives services through the province's Extra-Mural Program, roughly 54% of respondents said they were very satisfied in the Shippagan area, while almost 90% said they were satisfied in the Hillsborough area. http://bit.ly/2UmZs8j

Extracts in New Brunswick's palliative care strategy[1]

Enhance access to in-home services.

Develop skilled home support workers to deliver personal care, respite and relief.

1. 'Palliative Care in New Brunswick: A person-centred care and integrated services framework,' Department of Health, Government of New Brunswick, April 2018. [Noted in 23 April 2018 issue of Media Watch (#560, p.1). **Download/view at:** http://bit.ly/2VHqrM1

Specialist Publications

'We should care more about caregivers' (p.7), in *Canadian Medical Association Journal*.

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1. 'Beyond Satisfaction: Results of the 2018 edition of the Home Care Survey,' New Brunswick Health Council, March 2019. **Download View at:** http://bit.ly/2EH6cY0

N.B. The only mention of palliative care in the Council's report is a couple of words in the description of the province's Extra-Mural Program.

U.S.A.

Northern California man learns he's dying from doctor on robot video at Kaiser Permanente hospital

CALIFORNIA | ABC News (San Francisco) – 9 March 2019 – Ernest Quintana's family knew he was dying of chronic lung disease when he was taken by ambulance to a hospital, unable to breathe. But they were devastated when a robot machine rolled into his room in the intensive care unit that night and a doctor told the 78-year-old patient by video call he would likely die within days. "If you're coming to tell us normal news, that's fine, but if you're coming to tell us there's no lung left and we want to put you on a morphine drip until you die, it should be done by a human being and not a machine," his daughter Catherine Quintana said... Ernest Quintana died … two days after being taken to the Kaiser Permanente Medical Center emergency department in Fremont. Michelle Gaskill-Hames, senior vice president of Kaiser Permanente Greater Southern Alameda County, called the situation highly unusual and said officials "regret falling short" of the patient's expectations. But the hospital also defended its use of telemedicine and said its policy is to have a nurse or doctor in the room at the time of remote consultations. "The evening video tele-visit was a follow-up to earlier physician visits," Gaskill-Hames said in a written response. "It did not replace previous conversations with patient and family members and was not used in the delivery of the initial diagnosis." Hospital officials say the technology doesn't replace in-person conversations with the patient and loved ones. http://bit.ly/2EKbnXi

Specialist Publications

'Unintended consequences of the Right-to-Try Act for palliative care in pediatric oncology' (p.9), in *JAMA Oncology*.

International

Epilepsy expert issues warning over vital medication

U.K. (Scotland) | BBC News – 7 March 2019 – The U.K. government has said uninterrupted supply of medicines will be a priority in the event of a no-deal Brexit. Kathryn Hamling, head of clinical services at Highland Hospice, which offers PC services throughout the Highlands, said the impact of Brexit was already being felt in the hospice sector. She said: "We are aware that there may be some delay or some difficulty in getting some very necessary medication. This is a cohort of people who are often taking complex drug regimes and if there was a delay or an inability to access those drug regimes it would obviously affect the care we can give them. To have patients or families with that extra concern at a very distressing time is something we would want to avoid. So I think we would be looking for assurances about that access." She added: "I think one of the main areas where we are going to see an impact, and maybe we already are, is in the workforce. The majority of people being cared for at the end of life are at home or in the care homes, and a significant proportion of people who work in those areas are non-U.K. European Union nationals, and if that is going to reduce, then a service that is already stretched is going to be stretched even further." https://bbc.in/2ESx8ph

Noted in Media Watch 10 December 2018 (#593, p.6):

- U.K. (Scotland) | Scottish Partnership for Palliative Care (SPPC) – 2 December 2019 – **'Scottish Partnership for Palliative Care position paper on the impacts of Brexit on palliative and end-of-life care.'** The position paper acknowledges the uncertainties currently surrounding Brexit and describes its approach to conducting analysis in spite of this uncertainty. After providing some background on SPPC and palliative care (PC) in Scotland, the paper describes current "non-Brexit" challenges in PC. The impact of Brexit on the key domains of workforce, scientific research, medicine supply and funding are then considered. The position paper contains the findings of a recent SPPC survey designed to capture the views of people who are involved in a professional capacity in providing care for people approaching the end of life (EoL) in Scotland. **Download/view at:** http://bit.ly/2ETeayI

Ombudsman welcomes further Health Services Executive support for end-of-life care…

IRELAND | *The Dundalk Democrat* – 6 March 2019 – Ombudsman Peter Tyndall has welcomed the Health Services Executive's announcement of an additional six coordinators in hospitals for end-of-life care (EoLC)… The HSE said it will also fund training for 90 staff as 'Final Journey' facilitators. The 'Final Journeys' training programme is a major part of the Hospice Friendly Hospitals initiative which supports staff to deliver good EoLC.[1] An Ombudsman report into EoLC, 'A Good Death,' described some of the issues raised in complaints the Ombudsman received, and the impact on dying patients and their loved ones. A progress report published in 2018 highlights improvements in the provision of care as well as some areas that need further attention. The six new posts combined with the existing seven end-of-life coordinators means that every hospital group and all large teaching hospitals in Ireland will have a member of staff dedicated to the continuous improvement in EoLC. http://bit.ly/2EDNwZg

Specialist Publications

'End-of-life care in hospital: An audit of care against Australian national guidelines' (p.6), in *Australian Health Review.*

'A review and analysis of new Italian law 219/2017: "Provisions for informed consent and advance directives treatment,"' (p.7), in *BMC Medical Ethics.*

'Ireland's Assisted Decision Making Capacity Act: The potential for unintended effects in critical emergencies – cross-sectional study of Advanced Paramedic decision making' (p.9), in *Irish Journal of Medical Science*.

'Intrahospital, mobile palliative care teams in Wallonia (Belgium): Fossil or renewable energy?' (p.12), in *Médecine Palliative*.

1. 'Hospice Friendly Programme,' Irish Hospice Association. [Noted in 8 September 2014 issue of Media Watch (#374, p.13)] **Download/view at:** http://bit.ly/2NRbQLy

Noted in Media Watch 15 October 2018 (#585, p.11):

- IRELAND | *The Irish Medical Times* – 11 October 2018 – **'Improvements are needed in end-of-life care: Ombudsman.'** Hospital and hospice staff need to improve the way they deal with dying patients and recently bereaved families, a report from the Ombudsman has found.[1] The report is a follow-up to Ombudsman Peter Tyndall's 2014 report, which described some of the issues raised in complaints he received about end-of-life care.[2] In his report, Tyndall said that the introduction of two new training schemes, the 'Final Journeys' workshop and the 'Breaking Bad News' [*sic*] training programme,[3,4] were "giving staff the confidence to hold compassionate and sensitive conversations with dying patients and their families." He added: "Poor communication is a regular feature of complaints to the Ombudsman." **Full text:** http://bit.ly/2ETs6c1

    1. 'A Good Death Progress Report: Developments in End-of-Life Care in Irish Hospitals since the publication of the Ombudsman's report in 2014,' Office of the Ombudsman, September 2018. [Noted in 24 September 2018 issue of Media Watch (#582, p.5)] **Download/view at:** http://bit.ly/2NOQFK6

    2. 'A Good Death: A Reflection on Ombudsman Complaints about End-of-Life Care in Irish Hospitals,' Office of the Ombudsman, June 2014. [Noted in 30 June 2014 issue of Media Watch (#364, p.6)] **Download/view at:** http://bit.ly/2TpigaL

    3. 'Final Journeys,' Irish Hospice Foundation. **Download/view at:** http://bit.ly/2TszWI5

    4. 'Delivering Bad News,' Irish Hospice Foundation. **Download/view at:** http://bit.ly/2IYbkwu

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http://bit.ly/2ThijkC

Russia's President Putin signs palliative care bill into law

RUSSIA | Russian Legal Information Agency (Moscow) – 6 March 2019 – The law specifies the concept of palliative care that involves a package of measures including medical treatment, after care and psychological actions aimed to improve the quality of terminally ill patients' living and is oriented to the amelioration of pain. The law confirms the right of terminal patients to pain relief including drug preparations and medical devices. Such assistance is to be rendered on an outpatient basis and at hospitals by specially trained health workers. Palliative patients are also to receive social and psychosocial support as well as religious care, according to the law. Volunteers, social workers and representatives of religious confessions would be involved in these services. The respective amendments have been introduced to the law "On the Fundamentals of Public Health Protection in the Russian Federation." http://bit.ly/2H4q4YG

Britain's elderly are living in "real fear" of moving into care homes after they get worse in a third of council areas

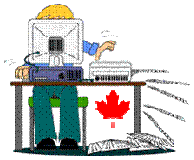
U.K. (England) | *The Daily Mail* (London) – 5 March 2019 – Care homes are getting worse in a third of local areas, a report reveals…[1] It warns that many elderly residents have a "real fear" of moving into nearby homes as standards are so poor. In some local councils, including Manchester and Portsmouth, as many as four in ten care homes are failing. The analysis by the charity Independent Age found that in 37% of authorities, the number of homes rated "inadequate" or "requires improvement" had increased compared to 2018. The authors looked at inspection reports from the Care Quality Commission (CQC)… Care homes should – in theory – be improving as they are inspected on a regular basis by the CQC, which identifies failings. But the analysis found that the number of councils where care homes were getting worse had increased. https://dailym.ai/2Ti2FcZ

1. 'Care home performance across England – 2019,' Independent Age, March 2019. **Download/view at:** http://bit.ly/2SJCy9z

Hospice access campaign push

U.K. (England) | *The Doncaster Free Press* – 5 March 2019 – The Open Up Hospice Care campaign is led by national hospice and palliative care charity Hospice UK and highlights how hospice care is available beyond hospice in-patient units, including in people's homes. One in four people in the U.K. miss out on the care they need according to research – due to a range of reasons including late or a lack of referrals to hospice services and low levels of awareness about hospice care and where and when this support is available. Hospice UK and local hospices are working to tackle this through initiatives to extend care to more people, such as expanding community services and reaching out to the different groups of people who have been missing out on vital support, including those caring for their loved ones at home. http://bit.ly/2H3qYES

N.B. See 'Seven in ten U.K. adults say that support from a local hospice would make them feel more confident in supporting a loved one with a terminal condition at home,' Hospice UK, March 2019. **Download/view at:** http://bit.ly/2C76sPE



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

Specialist Publications

Towards a guiding framework for prison palliative care nursing ethics

ADVANCES IN NURSING SCIENCE | Online – 1 March 2019 – The number of people aging and dying behind bars is growing, bringing greater attention to the need for prison palliative care (PC). While this trend has led to increased scholarship, a focus on understanding the most effective way to deliver prison palliative care (PC) has overshadowed thinking about why the need itself has arisen, as well as deeper ethical thinking about how the nursing profession should respond. This article interweaves four strands of analysis – contextual, relational, social, and political – to produce a framework to guide ethical action in prison PC nursing, relevant to practice, research, policy, and education. **Abstract:** http://bit.ly/2EDwVVs

Publishing Matters

'Breaking down the paywall that blocks access to the world's academic research' (p.16), in CBC's 'Second Opinion.'

'The past, present & future of truth' (p.17), posted on the website of the Frederick S. Pardee Center for the Study of the Longer-Range Future.

N.B. Additional articles on Canada's aging prison population noted in 25 June 2018 issue of Media Watch (#569, p.2). A compilation of selected articles, reports, etc., on end-of-life care in the prison system noted in past issues of the weekly report is posted on the Palliative Care Network website. **Download/view at:** http://bit.ly/2RdegnL

Effects of a primary palliative care educational system for teaching learners at different levels of training

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 March 2019 – The palliative care (PC) rotation has been shown to improve PC knowledge in medical students (MS) and internal medicine (IM) residents, and PC specialists stand poised to direct the primary PC education of learners at different levels of training. To concurrently teach learners of different levels of training on a busy PC service, the authors created an educational system that emphasizes management of learner schedules, organization of teaching activities, faculty development to improve teaching skills, and learner self-evaluation. Both MS and IM residents showed an improvement in self-assessed competence as well as increased comfort level with seriously ill patients after PC rotation. **Abstract:** http://bit.ly/2C9CDhx

The provision of palliative care for non-cancer patients with advanced disease: Equity does matter

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 5 March 2019 – According to the World Health Organization, the main mission of palliative care (PC) is to optimize the quality of life of patients with serious chronic disease, as well as their caregivers, by providing biopsychosociospiritual care. However, historically, the primary focus of PC is on providing care for cancer diseases. Based on the current literature, it is assumed that PC is not provided for many chronic diseases on a regular basis and in many cases, a clinical guideline does not exist for providing PC. **Abstract:** http://bit.ly/2TBPMtm

Noted in Media Watch 1 October 2018 (#583, p.17):

- *PLOS ONE* | Online – 25 September 2018 – **'Diagnosis-related differences in the quality of end-of-life care: A comparison between cancer and non-cancer patients.'** Cancer, chronic heart failure (CHF) and chronic obstructive pulmonary disease (COPD) in the advanced stages have similar symptom burdens and survival rates. Despite these similarities, the majority of the attention directed to improving the quality of end-of-life care (EoLC) has focused on cancer. This study highlights the presence of significant differences in the quality of EoLC received in the last month of life by COPD and CHF compared with cancer patients. **Full text:** http://bit.ly/2TsMFEl

Cont.

Noted in Media Watch 1 May 2017 (#510, p.14):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 April 2017 – **'Comparing the palliative care needs of those with cancer to those with common non-cancer serious illness.'** The authors conducted a cross-sectional, retrospective analysis of the characteristics and symptoms of patient's with renal disease (ESRD), heart failure (HF), chronic obstructive pulmonary disease (COPD), and cancer at the time of first specialty palliative care (PC) referral. Patients with COPD, ESRD and HF were less functional and more likely to be hospitalized at time of referral to PC than cancer patients. **Full text:** http://bit.ly/2EOSfaP

Stakeholder perspectives on the biopsychosocial and spiritual realities of living with ALS: Implications for palliative care teams

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 March 2019 – The purpose of this study was to generate a rich description of the realities of living with amyotrophic lateral sclerosis (ALS), equipping palliative care (PC) teams with an in-depth understanding of the experiences and needs of patients with ALS and their family caregivers. Identified themes were organized into two broad categories: 1) Biopsychosocial needs of patients with ALS and family caregivers; and, 2) The impact of ALS on spiritual and emotional well-being. Quantitative data supported the recognized themes, particularly with regard to challenges associated with preserving independence, securing sufficient social support, and managing the emotional complexities of the disease. The findings illustrate the intricacies of living with ALS and the importance of eliciting individualized values when caring for patients with ALS and their families. The complex biopsychosocial needs experienced by patients and family caregivers suggest numerous opportunities for meaningful PC involvement. **Abstract:** http://bit.ly/2EtJrqn

N.B. Additional articles on PC for people living with ALS noted in 25 February 2019 issue of Media Watch (#603, pp.5-6).

End-of-life care in hospital: An audit of care against Australian national guidelines

AUSTRALIAN HEALTH REVIEW | Online – 5 March 2019 – A retrospective medical record audit of deceased in-patients was conducted at one public and one private hospital in Melbourne, Australia. Ten variables … were used to evaluate end-of-life care (EoLC). Most patients (87.2%) had a limitation of medical treatment. In 91.97% of cases, a written entry indicating poor prognosis preceded a documented decision to provide EoLC, with a documented decision noted in 81.1% of cases. Evidence of pastoral care involvement was found in 41.6% of cases, with only 33.1% of non-palliative care (PC) patients referred to specialist PC personnel. An EoLC pathway was used in 51.1% of cases. There is clear room for improvement in providing patient-centred care, increasing family involvement and teamwork, describing and enacting goals-of-care and using triggers to prompt care. Differences between public and private hospitals may be the result of differences in standard practice or policy and differences in cultural diversity. **Abstract (w. list of references):** http://bit.ly/2GZ9QjD

Recruiting general practitioners for palliative care research in primary care: Real-life barriers explained

BMC FAMILY PRACTICE | Online – 5 March 2019 – Recruitment in primary palliative care research is difficult for many reasons. This study shows a high level of interest from the GPs to be involved, but also produced high GP dropout rates and low data completion. Suggestions for future recruitment and quality improvement efforts in this field are formulated. The key is to offer a well-defined intervention which clearly benefits the GPs and/or the patients and a well-designed research protocol which takes the research burden as much as possible away from GPs and patients. **Full text:** http://bit.ly/2H61nLE

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A review and analysis of new Italian law 219/2017: "Provisions for informed consent and advance directives treatment"

BMC MEDICAL ETHICS | Online – 4 March 2019 – Recent developments in the cultural, juridical, and social debate have paved the way for a law which insists on a more patient-centred standard of medical care in the best interests of the patients and which is an attempt to regulate all the complex issues surrounding end-of-life care. This article highlights the fundamental point of the new Italian law: consensus as an essential connotation of the treatment relationship. This is not limited to the acceptance/rejection of a medical treatment but expands in time and is projected into the future through shared care planning and advance directives which act as tools of self-determination and the manifestation of the beliefs and preferences of someone who is unable to make decisions. These principles are perfectly in line with the idea of appropriate care, as evaluated from two different perspectives, one of scientific adequacy and the other commensurate with the individual's resources, fragility, values, and beliefs. The operational challenges in achieving this normative goal still remain, among which is the goal of balancing the clinician's right to conscientious objection and the patient's right to self-determination. These challenges deserve the close attention of Italian healthcare professionals and policymakers. **Full text:** http://bit.ly/2H0NsX6

Noted in Media Watch 26 November 2018 (#591, p.16):

- *MINERVA ANESTESIOLOGICA* | Online – 21 November 2018 – **'The Italian law on informed consent and advance directives: Its impact on intensive care units and the European legal framework.'** After several years of debate on the need to approve such a law, the focus has now shifted to the assessment of the legislative provisions and their impact on clinical practice. The authors firstly offer an overview of the findings from the empirical research regarding the use of the different legal tools in the field of intensive care medicine; secondly, they present the tools now provided by law no. 219/2017 particularly with regard to the decision-making processes in the intensive care unit; thirdly, the authors offer a comparison between the new Italian law and other European legal orders, with special reference to France, Spain, Germany and England. **Abstract:** http://bit.ly/2HcWI9Y

We should care more about caregivers

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2019;191(9):E245-E246. Every day, about 28% of Canadians provide care for a family member, friend or neighbour, and nearly half will do so at some point. Although many Canadians with chronic conditions and disabilities need care, the most common needs requiring caregiver help are age related. With 93% of older Canadians living at home, unpaid or informal caregivers provide up to 75% of care services, which equates to about $24-$31 billion in unpaid work annually. We must and can to do more to acknowledge and support informal caregivers in bearing this burden. Over the next 20 years, the number of older Canadians requiring assistance will double, yet there is a shrinking pool of informal caregivers. Changes in demographics and family structures are reducing the ratio of caregivers to older adults, and many potential caregivers are unwilling to assume responsibilities or are exiting the role early. While caregiving for older adults can be rewarding, it is increasingly demanding, complex and stressful. The average informal caregiver spends 19 hours a week on caregiving duties, and 1 in 10 provides more than 30 hours of care per week. Despite little to no training, they are expected to provide medical and nursing care in the home, navigate complicated health and long-term care systems, and serve as substitute decision makers. Many Canadian caregivers report distress, including 26% of those caring for older adults and 45% of those caring for people with dementia. Distressed caregivers experience a myriad of adverse outcomes, including deteriorations in mental and physical health, disruptions in social and family relationships, and increased risk of death. Although bolstering home care and respite care is essential for supporting both caregivers and care recipients, most Canadian caregivers do not have access to caregiver-specific education and supports despite evidence that these can improve their well-being and that of the care recipient. **Full text:** http://bit.ly/2Ts6E6Z

A scale to assess religious beliefs in end-of-life medical care

CANCER | Online – 2 March 2019 – Studies postulate that certain religious beliefs related to medical care influence the end-of-life (EoL) medical decision-making and care of patients with advanced cancer. Because to the best of their knowledge no current measure explicitly assesses such beliefs, in this study the authors introduced and evaluated the Religious Beliefs in EoL Medical Care (RBEC) scale, a new measure designed to assess religious beliefs within the context of EoL cancer care. The scale consists of 7 items designed to reflect religious beliefs in EoL medical care. Its psychometric properties were evaluated in a sample of 275 patients with advanced cancer… The scale proved to be internally consistent, unidimensional, positively associated with other indicators of patients' religiousness and spirituality …, and inversely associated with patients' terminal illness understanding and acceptance…, suggesting its potential clinical usefulness in promoting informed EoL decision making. **Abstract:** http://bit.ly/2ITgxFF

Related

- *CANCER* | Online – 2 March 2019 – **'Religious beliefs influencing aggressive end-of-life care preferences: A measurement advance and continued challenges.'** The RBEC scale is a significant addition to the literature on the complicated relationships between religion, spirituality, and the treatment preferences of patients with advanced cancer. This editorial highlights several suggestions for additional refinement of the measure. **Abstract:** http://bit.ly/2VBS757

Noted in Media Watch 18 June 2018 (#568, p.8):

- *HEC FORUM* | Online – 7 June 2018 – **'When religion and medicine clash: Non-beneficial treatments and hope for a miracle.'** Differences of opinion between physicians and patients/families about what are appropriate interventions in specific clinical situations are often fraught with highly strained emotions, and perhaps none more so when the family bases their desires on religious belief. **Abstract (inc. list of references):** http://bit.ly/2VBVYiB

Noted in Media Watch 13 March 2017 (#503, p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(2):115-119. **'Hope for a miracle: Treatment requests at the end of life.'** This article explores requests for aggressive treatment stemming from strongly held religious beliefs and overarching hope for a miracle. A case example highlights the complexities of religious coping, belief in miracles, and requests for life-prolonging treatment at the end of life. **Abstract:** http://bit.ly/2TfAECV

N.B. Additional articles on religious coping in the context of EoL care noted in 11 April 2016 issue of Media Watch (#457, pp.10-11).

The new Heart Failure Association of the European Society of Cardiology definition of advanced heart failure

CARDIAC FAILURE REVIEW, 2019;5(1):5-8. The clinical course of heart failure (HF) is characterised by progressive worsening of cardiac function and symptoms. Patients progress to a condition where traditional treatment is no longer effective and advanced therapies, such as mechanical circulatory support, heart transplantation and/or palliative care (PC), are needed. This condition is called advanced chronic HF. The Heart Failure Association first defined it in 2007 and this definition was updated in 2018. **Full text:** http://bit.ly/2SRWFCI

Extract from *Cardiac Failure Review* article

PC remains an important option to be indicated not only when treatment has failed but also as concomitant treatment in patients with severe disease.

N.B. Additional articles on PC for patients living with heart failure noted in 4 March 2019 issue of Media Watch (#604, p.8).

Eight things we would never do regarding end-of-life care in the ICU

INTENSIVE CARE MEDICINE | Online – 7 March 2019 – 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 (ICU). Intimate encounters with patients near the end of their lives form a foundational aspect of our vocation as intensivists. This article presents the authors' vision of eight top-tier concepts that should be embraced to usher in the best EoLC for all patients. They realize that not everyone will agree with these points and anticipate that our "eight things" will stimulate healthy discussion and debate. Furthermore, there might be caregivers throughout the world dealing with different cultural, legal, political, and ethical preconditions that make implementation of the approach presented within this manuscript difficult in some respects. **Abstract (w. list of references):** http://bit.ly/2XHEB1L

Ireland's Assisted Decision Making Capacity Act: The potential for unintended effects in critical emergencies – cross-sectional study of Advanced Paramedic decision making

IRISH JOURNAL OF MEDICAL SCIENCE | Online – 27 February 2019 – Irish legislation on advance healthcare directives – Assisted Decision Making Capacity Act 2015 (ADMC) proposes to change the basis of decision making from acting in the patient's best interests to following the expressed will and intentions of the patient. Refusal of life-saving care can occur, without sound reasons. The implications for care in life-threatening emergencies have not been explored among clinicians. An anonymous questionnaire survey of Advanced Paramedics (AP) covering awareness of the legislation, attitudes to and experience of refusal of care and potential actions in emergency scenarios now and if the legislation were in force. The scenarios covered end-of-life and deliberate self-harm situations potentially requiring resuscitation. Attitudes [of survey respondents] ranged from highly positive to highly negative in relation to the potential impact of the legislation on professional and operational responsibilities. Respondents described marked changes in whether they would offer resuscitation if the ADMC were in place. Irish legislation which changes the traditional basis of medical practice away from the best interests of the patient may affect the resuscitation practices of AP in life-threatening situations. It has significant implications for medical education, professional practice and clinician-patient interactions. This legislation and similar planned legislation may have implications for other European Union jurisdictions. **Abstract (w. list of references):** http://bit.ly/2tR3eeL

Unintended consequences of the [U.S.] Right-to-Try Act for palliative care in pediatric oncology

JAMA ONCOLOGY | Online – 7 May 2019 – In May 2018, the Right-to-Try (RTT) Act was signed into law, and it aims to increase access to investigational drugs for people with life-threatening illnesses. Although compassion is widely viewed as the motivating logic of the RTT Act, there are also indisputable economic and political motivations. These motivations reflect the mindset that the development and delivery of cures is being impeded primarily by risk-averse scientists and regulators, when what is required is a bold commitment to save dying people, unencumbered by timid procedural hurdles. Considerable attention has been paid to how this legislation differs from the U.S. Food & Drug Administration's existing Expanded Access regulations. However, during the bill's progress through Congress, some of the concerns raised about the potential for unintended negative consequences of the law have been missing from the discussion. The authors consider one of these concerns: the Act's potential to undermine palliative care for children with cancer. **Abstract:** http://bit.ly/2XFAuDg

N.B. Additional articles on the issue of "right-to-try" new experimental or investigational drugs noted in 4 February 2019 issue of Media Watch (#600, p.4).

Would this article be of interest to a colleague?

Death and dying: Tools to help respiratory therapists handle frequent exposure to end-of-life care

JOURNAL OF ALLIED HEALTH, 2019;48(1):72-75. Education and recognition of death anxiety are important for respiratory therapists. A vital component of respiratory therapy is managing mechanical ventilation and dealing with death and dying. For most institutions, respiratory therapy is a vital component of the rapid response team, code team, and trauma team. Removal of mechanical ventilation is a duty primarily bestowed upon the respiratory therapist. Exposure to death, on a frequent basis, can take an emotional toll and lead to burnout, stress, and increased turnover. Managers and leaders in the hospital must make efforts to provide counseling and education to support respiratory therapists and their ongoing exposure to death and dying. The author examines coping mechanisms for physicians and paramedics, resulting in tools that can be used to provide support to the respiratory therapist. **Abstract (via PubMed):** http://bit.ly/2EL7rGT

Medication safety in hospice and palliative care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(2):E1-E4. There is currently a serious opioid and medication diversion crisis in the U.S. Medications are being obtained illicitly and used inappropriately, and patients with serious illnesses are at risk of having their medications stolen. Medication safety is a top priority, particularly during today's opioids misuse crisis. For every one death from prescription opioids [in the U.S.], it is estimated that there are 10 treatment admissions for abuse, 32 emergency room visits for misuse or abuse, 130 people who become dependent on opioids, and 825 people who report non-medical use of these drugs. It is the position of the Hospice & Palliative Nurses Association that medication safety is an essential aspect of hospice and palliative nursing. Hospice and palliative nurses are instrumental in public education about medication safety for patient with serious illnesses, their family, and the community. **First page view:** http://bit.ly/2ITKvt5

We don't need unilateral DNRs: Taking informed non-dissent one step further

JOURNAL OF MEDICAL ETHICS | Online – 6 March 2019 – Although shared decision-making is a standard in medical care, unilateral decisions through process-based conflict resolution policies have been defended in certain cases. In patients who do not stand to receive proportional clinical benefits, the harms involved in interventions such as cardiopulmonary resuscitation seem to run contrary to the principle of non-maleficence, and provision of such interventions may cause clinicians significant moral distress. However, because the application of these policies involves taking choices out of the domain of shared decision-making, they face important ethical and legal problems, including a recent challenge to their constitutionality. In light of these concerns, the authors suggest a re-conceptualization of informed non-dissent as an alternative approach in cases where the application of process-based policies is being considered. **Abstract:** http://bit.ly/2VNN8yr

Helping the demand find the supply: Messaging the value of specialty palliative care directly to those with serious illnesses

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 March 2019 – Palliative care (PC) needs and services have experienced tremendous growth …, due to expansions of the evidence base coupled with a timely need in healthcare to demonstrate value and increase quality of care for those with serious illnesses. Having eclipsed its first decade as a recognized specialty, and despite remarkable growth in access to services, the majority of patients eligible for services still do not receive timely access to PC. This gap highlights the need to explore whether any shifts in strategy will help more patients receive the palliative services they need. **Abstract: (inc. link to references):** http://bit.ly/2NQ2XI6

The benefits and burdens of pediatric palliative care and end-of-life research: A systematic review

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 March 2019 – Pediatric palliative care (PC) requires research to mature the science and improve interventions. A tension exists between the desire to enhance palliative and end-of-life care for children and their families and the need to protect these potentially vulnerable populations from untoward burdens. Twenty-four studies met final inclusion criteria. The benefit or burden of PC research participation was reported for the child in 6 papers; siblings in 2; parents in 19; clinicians in 3; and, researchers in 5 papers. Benefits were more heavily emphasized by patients and family members, whereas burdens were more prominently emphasized by researchers and clinicians. No paper utilized a validated benefit/burden scale. The lack of published exploration into the benefits and burdens of those asked to take part in pediatric PC research and those conducting the research is striking. There is a need for implementation of a validated benefit/burden instrument or interview measure as part of pediatric palliative and end-of-life research design and reporting. **Abstract:** http://bit.ly/2SHXGx7

Related

- *DEATH STUDIES* | Online – 4 March 2019 – **'The experiences of physicians, nurses, and social workers providing end-of-life care in a pediatric acute-care hospital.'** Findings [of this study] demonstrated that participants experienced both professional and personal impacts of their work and employed various coping strategies... The acute care setting was found to create unique challenges in providing end-of-life care. Implications for policy and practice include promotion of both individual and institutional-level coping strategies and supports that meet the various needs of staff. Implications for research include a nuanced examination of differences in experiences among nurses, social workers and physicians. **Abstract:** http://bit.ly/2tT15Ps

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 March 2019 – **'Implications of pediatric palliative consultation for intensive care unit stay.'** The researchers' analytic sample included 777 admissions (11,954 hospital days), of which 100 admissions (13%) included pediatric palliative care (PPC) consultation. Principal patient demographics were age 8 ± 6 years, 55% male sex, 71% white race, and 52% commercial insurance. Cardiac diagnoses were most frequent (29%) followed by gastrointestinal (22%) and malignant (20%) conditions. Although total ICU stay was longer for admissions, including PPC consultation (compared to admissions where PPC was not consulted), the odds of being in the ICU on a given day were reduced by 79% after PPC consultation for children with cancer and 85% for children with non-oncologic conditions. **Abstract:** http://bit.ly/2XG1SkB

- *JOURNAL OF PEDIATRIC NURSING*, 2019;46(3):18-25. **'Parental perspectives on roles in end-of-life decision making in the pediatric intensive care unit: An integrative review.'** Little is known about how parents perceive their role or the role of healthcare providers (HCPs) during end-of-life decision making (EOL DM) in the context of the pediatric intensive care unit (PICU). The researchers' sample included eleven studies of parents and healthcare providers of critically ill children in the PICU and/or receiving inpatient pediatric palliative care, and bereaved parents of PICU patients. Most parents reported belief that EOL DM is within the domain of parental role, a minority felt it was a physician's responsibility. Parental EOL DM is rooted more firmly in emotion and perception and a desire to be a "good parent" to a child at EOL in the way they see fit than HCP recommendations or "medical facts." **Abstract:** http://bit.ly/2C6Yt53

- *PEDIATRIC BLOOD & CANCER* | Online – 8 March 2019 – **'"What if?": Addressing uncertainty with families.'** Children with cancer and their families deal with uncertainty throughout their treatment course. Clinicians must help patients and families manage uncertainty by engaging them in discussions about their worries and fears. Too often, clinicians avoid or defer discussions about anticipated or worried-about future events – the "what ifs." Failing to engage in these conversations may lead to increased distress. The authors have developed a framework for having "what if" conversations with patients and families that enables providers to explore families' informational and emotional needs. This framework may enable providers to improve families' prognostic understanding, explore concerns, and examine preferences and goals of care. **Abstract:** http://bit.ly/2STRCld

Intrahospital, mobile palliative care teams in Wallonia (Belgium): Fossil or renewable energy?

MÉDECINE PALLIATIVE | Online – 1 March 2019 – The authors share their reflections regarding the current changes that intrahospital, mobile palliative care teams (MPCT) in Wallonia (Belgium) face. They also propose a few forward-looking considerations to meet the challenges these teams are now confronted with. After providing an overview of the field's current status, the authors propose a change of vision. The palliative designation recognizes a passage, a transition from the curative to the palliative. The notion of "passage," of "transition" is fundamental. The intrahospital, MPCT have an educational role to play in the reimplantation of death, and in the possibilities that we have to evoke it. It entails re-entering an appeasing dynamic in bringing up the possible death. It is thus necessary to evolve towards a circular representation of care that includes both curative care and palliative care; the new vision being for an earlier consideration of the latter. The authors point out the objectives and the mission of the intrahospital, MPCT; those to be continued or developed, specifying the necessary mandates and urging the hospital institution in recognizing them. **Abstract:** http://bit.ly/2EznTc3

N.B. French language article.

Do mention the D word

MEDSCAPE | Online – 4 March 2019 – Doctors sometimes find it hard to talk to their patients about death. There are many reasons why it may be a struggle, not least because it can be a difficult and sensitive conversation to have. A recent report by the Royal College of Physicians suggested that doctors need to improve their conversations with patients with terminal illnesses or chronic conditions, to handle them in a more timely way and with more compassion and confidence.[1] So why is it such a difficult conversation? Doctors may not be comfortable dealing with the reaction of the patient and their families. People can have a myriad of responses; from shock and denial to feeling offended or being utterly bereft. It can be challenging for a doctor to broach the subject, especially if they don't have a long-term doctor-patient relationship and are unaware of the specifics of the situation. Some patients and their families may regard the conversation as an indication the medical profession is giving up on them. Cultural differences can also be important with some nationalities, religions or ethnic groups being less comfortable with the concept of limiting treatment, stopping treatment or moving towards palliative care. **Full text:** https://wb.md/2Tzuxsa

1. 'Talking about dying: How to begin honest conversations about what lies ahead,' Royal College of Physicians, October 2018. [Noted in 22 October 2018 issue of Media Watch (#586, p.3)] **Download/view at**: http://bit.ly/2IT5uMJ

Related

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 4 March 2019 – **'End-of-life communication: Personal sketches beyond protocols.'** There is a deep-rooted and long-standing conviction in modern medicine that the end of life (EoL) is largely a biological process marked by multi-organ dysfunction with an imperious need for targeted technical and pharmacological interventions. Reducing EoL human experience to a biomedical event erodes one of the most meaningful and important life experiences: a complex, intimate encounter towards ourselves, a profound existential and psychological dialog. Communication provides a means to assure that the humanity of patients is maintained and possibly strengthened. In this encounter with tangible and glimpsed death – perhaps for the most visceral, intimate, and profound in our lives – communication is a special place that "saves," in part, the remainings of ourselves after they are amputated by disease and adversity. **First page view:** http://bit.ly/2HfLotF

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.18.

Materiality and the body: Explorations at the end of life

MORTALITY | Online – 7 March 2019 – Questioning the material status of a dead body is a challenge: on the one hand, a corpse seems to be nothing more than the physical remains of a person that once was – and is now gone. On the other hand, the dead body is still the material representation of the social identity that used to "inhabitate" this body. Not least for it's striking similarity, one person's corpse is thus often considered the post mortem status of his or her ‚self'. When taking a closer look at the difference between living (in the sense of "ensouled") bodies and their allegedly materialistic counterparts, the separating effect dissolves. As a consequence, certain concepts of sociological theory become interpretedable in a truly transfrontier manner. By drawing upon empirical data from original research carried out by the authors concerning dying, death and bereavement, this article is an attempt to approach the materiality of the dead body in the light of it's various forms of social utilisation. **Abstract:** http://bit.ly/2CaCOcd

Advance care planning for older people: The influence of ethnicity, religiosity, spirituality and health literacy

NURSING ETHICS | Inprint – Accessed 5 March 2019 – Older people from cultural and ethnic minorities have low access to palliative or end-of-life (EoL) care and there is poor uptake of Advance Care Planning by this group across a number of countries where advance care planning (ACP) is promoted. For many, religiosity, spirituality and health literacy are significant factors that influence how they make EoL decisions. Health literacy issues have been identified as one of the main reasons for a communication gaps between physicians and their patients in discussing EoL care, where poor health literacy, particularly specific difficulty with written and oral communication often limits their understanding of clinical terms such as diagnoses and prognoses. This then contributes to health inequalities given it impacts on their ability to use their moral agency to make appropriate decisions about EoL care and complete their advance care plans. Currently, strategies to promote ACP seem to overlook engagement with religious communities. Consequently, policy makers, nurses, medical professions, social workers and even educators continue to shape ACP programmes within the context of a medical model. The ethical principle of justice is a useful approach to responding to inequities; and, to promote older peoples' ability to enact moral agency in making such decisions. **Abstract:** http://bit.ly/2EyxLmp

Related

- *BMC PALLIATIVE CARE* | Online – 7 March 2019 – **'Discussing end of life wishes – the impact of community interventions?'** The findings of this study suggest that well-designed awareness-raising and educational events, delivered in a sensitive manner, can prompt the public to consider EoL preferences and discuss these with the people closest to them, and may increase recipient's confidence in having those conversations. These types of intervention have the potential to reach beyond the immediate recipients, as attendees talk to others about issues, or even host their own similar events. The events evaluated in this study appeared to be relevant and effective for all age groups, but were most relevant and effective for those aged 45 to 74. Further research might identify interventions more suitable for younger and older age groups, and those who would not be reached by events like these. **Full text:** http://bit.ly/2XP8soK

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 March 2019 – **'Volunteer involvement in advance care planning: A scoping review.'** This scoping review has identified the emerging literature on volunteer involvement in advance care planning (ACP), demonstrating a lack of systematic approach to implementation, with the included studies often providing limited detail in the scope of volunteers' roles in ACP. Future research should aim to evaluate the effectiveness of volunteers in ACP, both in terms of the impact on volunteers and on person-centred outcomes, such as acceptability of the program and whether it leads to greater adherence to a person's health treatment preferences. In addition, future models should consider existing frameworks for volunteer involvement in organizations in defining the scope of volunteers' role in ACP. **Full text:** http://bit.ly/2SR5Fry

Socioeconomic factors affecting access to preferred place of death: A qualitative evidence synthesis

PALLIATIVE MEDICINE | Online – 8 March 2019 – Existing quantitative evidence suggests that at a population level, socioeconomic factors affect access to preferred place of death. However, the influence of individual and contextual socioeconomic factors on preferred place of death are less well understood. A total of 13 articles, reporting on 12 studies, were included in the synthesis. Two overarching themes were identified: "human factors" representing support networks, interactions between people and decision-making and "environmental factors," which included issues around locations and resources. Few studies directly referenced socioeconomic deprivation. The main factor affecting access to preferred place of death was social support; people with fewer informal carers were less likely to die in their preferred location. Other key findings included fluidity around the concept of home and variability in preferred place of death itself, particularly in response to crises. There is limited U.K.-based qualitative research on socioeconomic factors affecting preferred place of death. Further qualitative research is needed to explore the barriers and facilitators of access to preferred place of death in socioeconomically deprived U.K. communities. In practice, there needs to be more widespread discussion and documentation of preferred place of death while also recognising these preferences may change as death nears or in times of crisis. **Abstract:** http://bit.ly/2EMpjQp

Enabling patients with advanced chronic obstructive pulmonary disease to identify and express their support needs to healthcare professionals: A qualitative study to develop a tool

PALLIATIVE MEDICINE | Online – 5 March 2019 – This study outlines the development of an evidence-based, designed-for-purpose, tool to help patients with advanced chronic obstructive pulmonary disease (COPD) identify and express their support needs to healthcare professionals. The developed Support Needs Approach for Patients (SNAP) tool is distinct from existing patient needs assessment tools in that it is: 1) Comprehensive, yet concise; and, 2) Helps patients directly identify and express areas where they may require more support to manage life with advanced COPD. The SNAP tool now requires validating before it can be used in clinical practice to enable delivery of person-centred care through the SNAP intervention. **Full text:** http://bit.ly/2C8bzzc

Meaning of work and personal protective factors among palliative care professionals

PALLIATIVE & SUPPORTIVE CARE | Online – 7 March 2019 – Healthcare professionals who work in palliative care (PC) units face stressful life events on a daily basis, most notably death. For this reason, these professionals must be equipped with the necessary protective resources to help them cope with professional and personal burnout. Despite the well-recognized importance of the construct "meaning of work," the role of this construct and its relationship with other variables is not well-understood. The authors objective was to develop and evaluate a model that examines the mediating role of the meaning of work in a multidisciplinary group of PC professionals. Using this model, the authors sought to assess the relationships between meaning of work, perceived stress, personal protective factors (optimism, self-esteem, life satisfaction, personal growth, subjective vitality), and socio-demographic variables. The proposed model showed a high explanatory value for the meaning professionals give to their work and also for perceived stress, personal protective factors, and socio-demographic variables. The authors findings could have highly relevant practical implications for designing programs to promote the psychological well-being of healthcare professionals. **Abstract (w. references):** http://bit.ly/2HiTjGG

N.B. Additional articles on burnout (i.e., compassion fatigue) noted in 25 February 2019 issue of Media Watch (#603, p.6).

The deteriorating patient representative on a palliative care quality committee: Ethical and practical considerations

PALLIATIVE & SUPPORTIVE CARE | Online – 6 March 2019 – This case study describes the involvement of a patient representative on a palliative care (PC) committee and outlines some of the issues that arose as her health deteriorated. A summary of the increasing involvement of patient representation within healthcare governance is provided, and some of the challenges raised by the case, many of which may be relatively unique to PC, are discussed. It is hoped that presentation of this fairly novel scenario provides other PC providers with the opportunity to consider their own processes and practices around managing a similar situation should it occur in their healthcare setting. **Abstract:** http://bit.ly/2HkVsl2

Matching response to need: What makes social networks fit for providing bereavement support?

PLOS ONE | Online – 7 March 2019 – The research literature emphasizes the many negative consequences of bereavement, with increases in physical and psychological morbidity and mortality, and the disruption of social relationships being a primary determinant of both health and mortality. This puts the impact of bereavement squarely into a public health perspective that pursues health equity. The authors argue for adopting and strengthening a compassionate communities approach, not only for end of life care for dying people but also along the continuum of bereavement support. To support this approach, more research is needed into practice models that connect health and social services with local neighbourhoods and cultural life. Settings such as workplaces, schools, social and sporting clubs, and faith communities all have potential in making these connections. Fundamentally, however, the issue the authors have identified in relation to bereavement is one endemic to contemporary social organisation, a steady increase in social inequality and its negative consequences for well-being. Inequality contributes to social exclusion, particularly for those of reduced means. However, social inclusion is needed not only at end of life (EoL), but at all stages of life. Ideally, the networks that support us at EoL will be those that have supported us through life, and the EoL provides both a further opportunity for existing networks to be revived and strengthened, and new networks formed. However, the nature of contemporary society is that those with economic power may retain their social networks and be able to purchase professional support, while those without economic power may lack access to both. Bereavement support is about the circles of care that are formed during the caring process, combined with peer support perhaps from people who were not part of the caring circle. It is imperative that these circles transcend social divisions and become available to all members of the community. **Full text:** http://bit.ly/2SQocUX

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 March 2019 – **'Impact of medical assistance in dying (MAiD) on family caregivers.'** The aim of this article is to explore the experience of medical assistance in dying (MAiD) from the family caregiver perspective, namely their beliefs and opinions about the intervention, how the process of MAiD impacts them, how the intervention shapes their view of their loved one's quality of death, and the psychosocial outcomes after the passing of their loved one. Beyond the literature, challenges within both the clinical and research realms are discussed and future directions are offered. While MAiD is currently legal in only a small number of countries, a better understanding of the impact of MAiD will help inform policy and legislation as they are developed in other jurisdictions. **Abstract:** http://bit.ly/2NFkvjY

- *CANADIAN JOURNAL OF HOSPITAL PHARMACY*, 2019;72(1). **'Knowledge and attitudes of hospital pharmacy staff in Canada regarding medical assistance in dying (MAiD).'** Overall, pharmacy staff across the country who responded to this survey – 607 pharmacists, 273 pharmacy technicians, and 160 pharmacy assistants – tended to be supportive of MAiD. Moreover, technicians and assistants who responded to this survey tended to be more supportive of MAiD than pharmacists, including attitudes regarding MAiD and willingness to carry out professional duties related to MAiD. The strongest predictors of supportive attitudes toward MAiD included respondents' knowledge of federal and provincial legislation, as well as the combination of degree of religious faith and the stance of one's faith on MAiD. **Full text:** http://bit.ly/2TqnCl5

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- *CULTURAL ANTHROPOLOGY*, 2019;34(1). **'Author(iz)ing death: Medical aid-in-dying and the morality of suicide.'** This article uncovers the complicated dialectic between authorship and authorization that characterizes medical assistance in dying and attendant moralities of purposive death, speaking to broader disciplinary concerns in the study of death and medicine. By stressing the primacy of debilitating, life-limiting illness in an aided death and by submitting such a death to the rationale and management of institutionalized medicine, advocates carve out a form of intentional death that occupies a category of its own. The diffusion of agency onto a patient's fatal illness, medicine, and the state enhances the moral and social acceptability of an assisted death, which becomes an authorized form of dying that looks different from the socially deviant act of suicide. **Full text:** http://bit.ly/2XwPcwd

- *THE HASTINGS REPORT*, 2019;49(1):4-5. **'Requests for physician assisted death and the assessment of capacity.'** There are many protections built into the state laws governing physician assisted death (PAD) [in the U.S.]. Proponents point out that patients must request access to PAD in person with their primary treating doctor, that the capacity-consent process is dictated by law, that there is mandatory reporting to state public health authorities, that there is a requirement for confirmation of prognosis by a second physician, and that there are provisions for mandated mental health professional assessment of patients' decisional capacity and mental status. In California, some health systems have opted to craft policies and procedures that establish more stringent standards for assessing capacity… **Full text:** http://bit.ly/2Hjdm7G

- *INTERNATIONAL JOURNAL OF FEMINIST APPROACHES TO BIOETHICS*, 2019;12(1):99-118. **'An argument for a substantively weak-dialogical approach to autonomy.'** This paper proposes a novel relational view of autonomy designed to overcome the inadequacies of procedural and substantive views of autonomy as they relate to physician-assisted suicide (PAS) requests for individuals with diminished cognitive functioning. Traditional and other relational views of autonomy regard a patient as an "isolated monad," ignore patients with limited personal autonomy, and overlook the contexts in which decisions like PAS are made. However, these weaknesses become the strengths of a synthesized relational view of autonomy, which enhances the personal autonomy of those with limited personal autonomy so that their PAS requests can be granted. **Abstract:** http://bit.ly/2GVZRvn

- *JOURNAL OF DISABILITY & RELIGION*, 2018;23(3):225-227. **'Special issue: Navigating impasses in bioethics – end of life, disability, and mental illness.'** The articles were originally presented at a 2017 research workshop, 'Navigating Impasses in Bioethics: End of Life, Disability & Mental Illness.' This workshop developed from a longstanding research project on contemporary understandings of illness and health and provided a unique setting to bring together different perspectives on the contentious debates on physician-assisted suicide for those suffering with mental health problems and disabilities. The authors explore both practical and theoretical aspects of the discussion and attempt to reimagine some of the key concepts involved, particularly the definitions of quality of life, dignity, autonomy, agency, consent, and mental capacity. **Journal contents page:** http://bit.ly/2UiDpzL

- *MORTALITY* | Online – 5 March 2019 – **'Escaping the "unprepared generation" trap: Discussions about euthanasia after a "completed life" in The Netherlands.'** The authors look at these discussion from a generational perspective: the present generation of older people has learned from the experiences of the previous generation that life may last longer than they want and it might be challenging to die in a humane way. The authors then briefly sketch the processes that led to the present call for euthanasia on the basis of "completed life" and disentangle the meaning of "completed life" in the existing literature. They present the results of their qualitative research… The authors then elaborate on individual expectations regarding the enactment of "completed life" euthanasia legislation. **Abstracts:** http://bit.ly/2H3KO2K

Publishing Matters

Breaking down the paywall that blocks access to the world's academic research

CANADA | CBC ('Second Opinion') – 9 March 2019 – Canada's academic librarians are cheering from the sidelines now that the University of California has cancelled its subscriptions with the academic publishing giant Elsevier. It was a clash of titans as the largest public university in the U.S. pushed back

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against the multi-billion dollar paywall blocking open access to the world's scientific knowledge. Tension has been building for years over the gradual privatization of academic literature, which has resulted in a handful of powerful international publishing companies controlling the dissemination of research. Elsevier is one of the largest academic publishers in the world, with prestigious journals including *The Lancet*... It leads the "big five" group that also includes Springer Nature, Wiley, Taylor & Francis, and Sage. Altogether they publish more than 11,000 journals. Last year Canadian university libraries paid more than $300 million for subscriptions to research journals including those containing papers generated by their own professors. It's become so expensive that some libraries have cancelled journals, leaving their students and faculty without access to some of that research. It creates a bizarre situation for students at the University of Calgary, who can't access the *Canadian Journal of Latin American & Caribbean Studies* even though it's published next door at the University of British Columbia. Increasingly public funding agencies are requiring scientists to make their research freely available as a condition of receiving grants. All three of Canada's major research funding agencies – the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada and Social Sciences, and the Humanities Research Council of Canada – have an open access requirement. Any research funded since 2015 must be freely available within 12 months. **Full text:** http://bit.ly/2C9DcYA

2019 Pardee Center Distinguished Lecture

The past, present & future of truth

FREDERICK S. PARDEE CENTER FOR THE STUDY OF THE LONGER-RANGE FUTURE | Online – Accessed 7 March 2019 – Marcia McNutt, President of the National Academy of Sciences … provided an overview of what she called the scientific hierarchy of truth, with the scientific method at the apex as "the most trusted approach to discovering the rules of the natural world," followed by consensus and, finally, individual studies. In this context, she discussed various public misperceptions about science. Whereas scientists acknowledge the abundance of evidence needed to establish a consensus, the public often does not distinguish between a consensus and an individual study. As a result, "truth gets wrapped up in the question of who you trust." McNutt … also explained the evolution of scientific literature and the peer review process. In the past, truth was established by asking a couple of simple questions: whether the work published in a high quality peer-reviewed journal, and whether the authors have a reputation for excellent, quality-controlled research. However, in recent decades, the size of the research enterprise has exploded with more than 2.5 million papers per year published by an increasingly international and interdisciplinary community of experts. This has led to a dramatic rise in scientific misconduct, particularly in countries where the research enterprise is growing the fastest, and a growing number of "predatory journals" with publication fees and poor or non-existent peer review and quality control. The response of scientists, McNutt argued, must be to demand independently replicated results and transparency with respect to data, methods, financial support, and conflicts of interest. **Download/view video of lecture at:** http://bit.ly/2UoSkIN

Media Watch: Editorial Practice

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