

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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Rather than “softening the blow” of introducing palliative care (PC), the term seems to condemn a patient to the very outcome that PC is tasked to ameliorate, namely, the limitation of life.

‘The limits of “life-limiting,”’ (p.11), in *Journal of Pain & Symptom Management*.

Canada

Local physician develops Plan Well Guide to help with end-of-life care

ALBERTA | *The Lethbridge Herald* – 19 March 2019 – Dr. Daren Heyland resides in Lethbridge, but is a critical care doctor at Kingston General Hospital, professor of medicine and epidemiology at Queen’s University, director of the Clinical Evaluation Research Unit Kingston General Hospital, and chair of Canadian researchers at the End of Life Network. Heyland conducted research on 120 random patients around the age of 65 ... to test his Plan Well Guide to help ease the stress of making end-of-life (EoL) decisions. “I have been studying research on the EoL for 20 years. It is a passion of mine because as an ICU doctor I am on the receiving end of people who are poorly prepared for serious illness, so I have seen too much suffering in both patients and family members,” says Heyland. “Most people go through life thinking they can do something tomorrow and think that this isn’t relevant to them, but this isn’t about terminal illness. This is about serious illness where there is a probability that you could die, but you could get better, too. You have to plan and think ahead a little bit so if something happens, what is important to you, what your treatment preferences are and how to verbalize it so that the family and doctor won’t be stressed in helping get the care

that is right.” The Plan Well Guide starts with being prescribed by the doctor for a patient to go online and go through the process of developing the plan. When individuals log into the site they are able to go through easy-to-understand information about the different types of care, serious illness decision making, understanding where their values are and developing the plan. <http://bit.ly/2Cn9wHl>

Specialist Publications

‘Ethical failings of College of Physicians & Surgeons of Ontario policy and the Health Care Consent Act: Case review’ (p.8), in *BMC Medical Ethics*.

‘Improving the medical assistance in dying (MAiD) process: A qualitative study of family caregiver perspectives’ (p.15), in *Palliative & Supportive Care*.

‘Assisted dying, suspended declarations, and dialogue’s time’ (p.15), in *University of Toronto Law Journal*.

U.S.A.

Medicare's hospice rules could make your doctor a criminal

WALL STREET JOURNAL | Online – 21 March 2019 – A doctor concludes that an elderly patient has less than six months to live. A second doctor disagrees. One of the predictions will be wrong. But was it false? For two years, the 11th U.S. Circuit Court of Appeals has wrestled with this question. The decision could ratify a trend of criminalizing medical judgments and jailing doctors based on disagreements with other doctors. <https://on.wsj.com/2HO9VXa>

Specialist Publications

'Results of a nationwide hospice and palliative care social work job analysis' (p.12), in *Journal of Social Work in End-of-Life & Palliative Care*.

Survey finds Idahoans aren't prepared for end-of-life care

IDAHO | *Idaho Press* (Nampa) – 20 March 2019 – Many Idahoans aren't thinking about or discussing end-of-life (EoL) care, a Boise State University survey found. Results of the survey – conducted by the Center for the Study of Aging at Boise State University – found only 14% of respondents discuss EoL care with their primary care physician, and 59% would prefer the doctor to prompt the conversation about death. The statewide survey conducted last year was meant to gather Idaho-specific information for health service providers about the needs of individuals nearing the EoL, according to the university. Less than 50% of respondents to the 2018 survey had taken steps on arrangements, such as creating a living will. A survey conducted in 2006 saw similar results, also emphasizing Idahoans lack information on how to address dying and death. <http://bit.ly/2URDo6g>

Death by 1,000 Clicks: Where electronic health records went wrong

KAISER HEALTH NEWS | Online – 19 March 2019 – Electronic health records (EHRs) were supposed to do a lot: make medicine safer, bring higher-quality care, empower patients, and yes, even save money. Boosters heralded an age when researchers could harness the big data within to reveal the most effective treatments for disease and sharply reduce medical errors. Patients, in turn, would have truly portable health records, being able to share their medical histories in a flash with doctors and hospitals anywhere in the country... But 10 years after President Barack Obama signed a law to accelerate the digitization of medical records – with the federal government, so far, sinking \$36 billion into the effort – America has little to show for its investment. Rather than an electronic ecosystem of information, the nation's thousands of EHRs largely remain a sprawling, disconnected patchwork. Moreover, the effort has handcuffed health providers to technology they mostly can't stand and has enriched and empowered the \$13-billion-a-year industry that sells it. By one measure, certainly, the effort has achieved what it set out to do: Today, 96% of hospitals have adopted EHRs, up from just 9% in 2008. But on most other counts, the newly installed technology has fallen well short. <http://bit.ly/2Fn2R1R>

Noted in Media Watch 30 July 2018 (#574, p.13):

- *JAMIA OPEN* | Online – 6 July 2018 – '**A systematic review of the use of the electronic health record for patient identification, communication, and clinical support in palliative care.**' The results of the studies presented contribute to the relevant understanding of the importance of early patient identification for palliative care (PC), patient reporting, PC summaries, advance care planning, communication, and electronic health record (EHR) enhancement for PC. The variation of methodology used in these studies resulted in one common and consistent theme, which is the EHR has yet to be optimized for its potential contributions to PC. Nevertheless, recent approaches of clinical decision support and patient-reported outcome measures demonstrated the EHR can be used to facilitate PC and to potentially result in improved PC, as well as a better quality of life for patients and their families. **Full text:** <http://bit.ly/2UJqsiD>



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Medicare payment policy: Hospice

MEDICARE PAYMENT ADVISORY COMMISSION REPORT TO CONGRESS (See p.311) | Online – 18 March 2019 – The Medicare hospice benefit covers palliative and support services for beneficiaries who are terminally ill with a life expectancy of six months or less if the illness runs its normal course. When beneficiaries elect to enroll in the Medicare hospice benefit, they agree to forgo Medicare coverage for conventional non-palliative treatment of their terminal illness and related conditions. In 2017, nearly 1.5 million Medicare beneficiaries (including more than half of decedents) received hospice services from 4,488 providers, and Medicare hospice expenditures totaled about \$17.9 billion.

Questions addressed by the report: 1) 'Are Medicare payments adequate in 2019?' ...and, 'How should Medicare payments change in 2020?'
Download/view at: <http://bit.ly/2Y5ZjIT>

Specialist Publications

'Medicare cost at end of life' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'How we use hospice: Hospice enrollment patterns and costs in elderly ovarian cancer patients,' (p.10), in *Gynecologic Oncology*.

Noted in Media Watch 31 December 2018 (#595, pp.4-5):

- *THE NEW YORK TIMES* | Online – 24 December 2018 – '**It's really hard to predict when someone will die.**' A widely held view is that much spending is wasted on "heroic" measures taken at the end of life (EoL). Are all the resources devoted to Medicare and Medicaid really necessary? Let's get one misunderstanding out of the way. The proportion of health spending at the EoL in the U.S. is lower than in many other wealthy countries.¹ Still, it's a tempting area to look for savings. Only 5% of Medicare beneficiaries die each year, but 25% of all Medicare spending is on individuals within one year of death.² However, the big challenge in reducing EoL spending, highlighted by a recent study, is that it is hard to know which patients are in their final year.³ <https://nyti.ms/2HvO3QW>

1. 'End-of-life medical spending in last twelve months of life is lower than previously reported,' *Health Affairs*, 2017;36(7):1211-1217. [Noted in 10 July 2017 issue of Media Watch (#520, pp.10-11)] **Full text:** <http://bit.ly/2CstQHo>

2. 'Medicare spending at the end of life: A snapshot of beneficiaries who died in 2014 and the cost of their care,' Kaiser Family Foundation, July 2016. **Full text:** <http://bit.ly/2TGxKqO>

3. 'Predictive modeling of U.S. healthcare spending in late life,' *Science*, 2018;360(6296):1462-1465. [Noted in 2 July 2018 issue of Media Watch (#570, p.3)] **Abstract:** <http://bit.ly/2Fk2LIJ>

Talking to children about terminal illness

THE NEW YORK TIMES | Online – 18 March 2019 – "One of the most difficult things we ever have to do is to tell a child he or she has a very serious condition and may not survive it, or that a parent has a condition they may not survive," said Dr. Alan Stein, a professor of child and adolescent psychiatry at the University of Oxford. Dr. Stein is the senior author on two articles published last week in the British medical journal *The Lancet*, which suggested guidelines for talking to children about life-threatening illness, one on when the illness is the child's own and the other on when a parent is ill. The doctors and other healthcare providers who are treating a parent with a serious illness often don't see this as their job, Dr. Stein said, but it can make a tremendous difference. Children are sensitive to changes in their parents' behavior, he said, and profoundly aware of parental mood and family atmosphere. "If we don't tell them, they have to cope with their anxieties by themselves," he said. "If it can be shared, they can get the kind of support they need, and the evidence is, this in many cases has benefits for the family system and the individual child." The guidelines call on the healthcare providers taking care of the child – or the parent – with the serious illness to help with this conversation, speaking directly with the child, when the child is sick, but also working with and supporting the parent, and offering specific age-appropriate advice. <https://nyti.ms/2W7z2YM>

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Noted in Media Watch 18 March 2019 (#606, p.7):

- **THE LANCET**, 2019;393(10176):1072. **‘Let’s talk with children about life-threatening diseases.’** One of the hardest things to do for any paediatrician is to talk with children or adolescents who have a potentially fatal illness about their diagnosis, treatment, and prognosis. There are many general guidelines and principles about communication with children. Two articles in this week’s issue of *The Lancet* review the literature and provide communication principles and examples based on an integration of the available research and the authors’ own clinical and academic perspective.^{1,2} **Full text:** <http://bit.ly/2HoKQIX>
 1. ‘Communication with children and adolescents about the diagnosis of their own life-threatening condition.’ **Summary (w. list of references):** <http://bit.ly/2TOSMCR>
 2. ‘Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent.’ **Summary (w. list of references):** <http://bit.ly/2XZZnd1>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- **NATIONAL CATHOLIC REGISTER** | Online – 18 November 2019 – **‘Assisted suicide battle plays out across several states.’** While state abortion laws are seizing headlines, a quieter battle for life is playing out across the country, as at least 15 states weigh legislation that would legalize assisted suicide. Key battleground states include Maryland, New Jersey, New York and New Mexico, where the leading advocate for the bills, Compassion & Choices, is focusing its efforts, according to Sean Crowley, a spokesman for the organization. Other states include: Arizona, Arkansas, Connecticut, Indiana, Iowa, Kansas, Massachusetts, Nevada, New York, Rhode Island, Utah and Virginia. “A lot of states are really on the cusp of legalizing it,” said Jennifer Popik, the director of medical ethics for National Right to Life. For a long time, Oregon was the only state that allowed assisted suicide, starting in 1997. A little more than a decade later, Washington followed suit. Then several more followed in short order through legislation or ballot initiatives: Vermont in 2013, California in 2015, Colorado in 2016 and Hawaii in 2018. The District of Columbia also legalized assisted suicide in 2016. A number of factors are driving the trend. <http://bit.ly/2TSe9U1>

International

End-of-life care in Korea

Health Ministry expands scope of “life-sustaining” treatments that can be discontinued

KOREA | *The Hankyoreh* (Seoul) – 20 March 2019 – The forms of life-sustaining treatments that patients or their family members are allowed to decline or discontinue in the terminal stages of life will be expanded... Discontinuation of life-sustaining treatment will also be allowed with the consent of the patient’s family members ... rather than by the patient’s doctor only, with relaxed conditions for family members who cannot be contacted to provide their consent. The term “life-sustaining treatment” refers to medical procedures without healing effects that are performed on terminal-stage patients whose conditions are no longer treatable by modern medicine; their sole aim is to prolong the patient’s life. The new measures expand the scope of procedures, which currently include cardiopulmonary resuscitation, respirator use, hemodialysis, and the administration of anti-cancer agents. <http://bit.ly/2ulfuo2>

End-of-life care in England

Specialist Publications

‘Advance directives in France: Do junior general practitioners want to improve their implementation and usage? A nationwide survey’ (p.8), in *BMC Medical Ethics*.

‘Prescription and deprescription of medications for older adults receiving palliative care during the last 3 months of life: A single-center retrospective cohort study [in France]’ (p.9), in *European Geriatric Medicine*.

Patients dying in hospital waiting for community care

U.K. (England) | *Health Service Journal* – 20 March 2019 – Terminally-ill patients are “needlessly dying in hospital” because they are waiting too long for specialist care packages... A report by Marie Curie suggests only around one in five clinical commissioning groups (CCGs) are meeting a two-day government timescale in which to provide fast-track Continuing Healthcare packages.¹ Continuing healthcare (CHC) is used to pay for the healthcare needs of an adult living in the community. The fast-track process has a speedy assessment and delivery timetable to help people who medics believe are likely to die soon. The charity collected 2017-2018 data from 149 out of 195 CCGs, via freedom of information requests. From this sample, around 10% of approved applications did not result in the patient receiving the care package. As 67,729 people were found eligible for fast-track CHC in England during the last financial year, a projection of the findings would suggest more than 6,700 could have died in hospital while waiting for community care. More than a third of approved packages were never provided in 25 CCG areas, while more than 40% were never provided in six areas. <http://bit.ly/2FpSMBa>

1. ‘When time really matters: Fast Track care at the end of life,’ Marie Curie, March 2019. **Download/view** at: <http://bit.ly/2TXfkS6>.

No dignity for the dying in Lebanon

LEBANON | *The Daily Star* (Beirut) – 19 March 2019 – Accessing end-of-life care is hard for Lebanese people at the best of times, with only one hospital in the country providing a dedicated service, leaving terminally ill patients reliant on non-government organizations (NGOs) for medical assistance and emotional support. However, for Lebanon’s most vulnerable communities suffering from terminal diseases, it is even more difficult to get the care they need to make their final days a little more bearable. Only the American University of Beirut (AUB) Medical Center Hospital has a permanent inpatient unit for palliative care (PC)... There is also a dearth of trained professionals, as only the medical schools at the AUB and University of Balamand integrate training on PC into their curricula. Even then, few medical students choose to specialize in this field – according to a study spearheaded by local PC NGO Balsam-Lebanese Center for Palliative Care. Lebanon has seen significant progress in its state of PC over the last decade, with the Health Ministry forming a National Committee for Pain Control & Palliative Care in 2011 and recognizing the practice as a medical specialty in 2013. <http://bit.ly/2HGzxoI>

Palliative care in the Eastern Mediterranean Region



The June 2017 issue of *Palliative Medicine & Hospice Care* focuses on palliative and end-of-life care in the Eastern Mediterranean Region, specifically Iran, Iraq, Israel, Jordan, Lebanon, Morocco, Palestine, Turkey and the United Arab Emirates. **Download/view** at: <http://bit.ly/2HI3q86>

N.B. See ‘Atlas of Palliative Care in the Eastern Mediterranean Region,’ a joint project of the Lebanese Center for Palliative Care and the Institute for Culture & Society, University of Navarra, Spain. [Noted in 22 May 2017 issue of *Media Watch* (#513, p.14)] **Download/view** at: <http://bit.ly/2Hufniy>



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

End-of-life care in Scotland

Palliative development post in the Borders is more than just a PATCH

U.K. (Scotland) | *The Southern Reporter* (Selkirk) – 19 March 2019 – A partnership between a Scottish charity and National Health Service (NHS) Borders has reaped results in the last two years. Palliation and the Caring Hospital (PATCH) has worked in partnership with NHS Borders, St Columba's Hospice, Edinburgh, and Queen Margaret University to deliver tailored and targeted staff development. Some 24 local nurses have participated in the PATCH course – learning over the course of five days how best to help patients receiving palliative care. This was followed by six months of mentored work on personal development relevant to their individual needs and clinical work. Now, for the first time, PATCH has agreed to fund a part time NHS Borders post in the hopes of helping even more nursing staff. <http://bit.ly/2Y7xsYR>

N.B. PATCH website: <http://bit.ly/2YbP3ij>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Australian Capital Territory) | *The Canberra Times* – 21 March 2019 – **'End-of-life inquiry lays out safeguards for voluntary euthanasia.'** A parliamentary committee has laid out safeguards for voluntary euthanasia in the Australian Capital Territory (ACT), should federal laws be changed to allow territories to legalise it in future. But the end-of-life choices inquiry made no explicit recommendation to introduce assisted dying, in recognition that the territory has no legal power to enact a scheme. The inquiry ... was tasked with looking at the options currently available to dying Canberraans and to consider what an assisted dying scheme in the ACT would look like. The committee has recommended the territory government assess the demand for palliative care (PC) in the ACT, look at extending funding for in-home PC, and further consider whether a dedicated PC ward at the Canberra Hospital is required. <http://bit.ly/2HBbLLG>

N.B. The authors of the report of the Inquiry into End of Life Choices in the ACT make 12 recommendations focused specifically on improvements in palliative care (PC) services. These highlight the need for improvement in a number of areas of PC delivery in relation to care equity, improving local government attention on PC delivery, and programs to support quality care provision. **Download/view the report at:** <http://bit.ly/2FtNiWk>

- U.K. | *The Daily Telegraph* (London) – 21 March 2019 – **'Royal College of Physicians drops their opposition to assisted dying, following controversial poll.'** The Royal College of Physicians (RCP) has dropped its opposition to assisted dying, following a controversial poll. The college will adopt a "neutral" stance after a survey of its 36,000 members about whether the law should be changed to permit doctor-assisted dying. The poll found 43.4% of respondents were opposed to a change in the law – little different to a finding of 44.4% when the poll was conducted in 2014. The number wanting the college to support assisted dying increased to 31.6% from 24.6%. Just 25% thought the RCP stance should be neutral – a fall from 31%, when medics were last polled. However, the terms of the new poll mean the college will now adopt a neutral position. The RCP had said it would do so, unless there was a 60% majority for or against. <http://bit.ly/2UMXkaj>
- *FORBES* | Online – 17 March 2019 – **'Euthanasia tourism: Is the European Union encouraging its growth?'** Euthanasia appears in the news usually as a result of a legal or ethical controversy surrounding the legality or illegality of its application. Most recently, though, it's getting attention again due to another controversial subject: euthanasia tourism, a strange pairing of words as "tourism" is typically associated with a joyful experience rather than a voluntary desire to end one's life. The most general definition of the phenomenon: When a person travels to a country offering euthanasia or assisted suicide as a legal option because the act is forbidden or more restrictive in his or her home country. Euthanasia tourism can be associated with "medical tourism," another phenomenon enabled by advances in medical technology, the increase of travel opportunities and the globalization of health-care. These factors have opened the doors for consumers to travel across borders or to overseas destinations to get medical treatment. Among the most popular travel-triggering treatments are cosmetic and dental surgery, cardio and orthopedic surgery, and organ and tissue transplants. Two recent cases have brought renewed global media attention to euthanasia tourism. <http://bit.ly/2CqXDIT>

Specialist Publications

Withholding and withdrawing life-sustaining treatment: Ethically equivalent?

AMERICAN JOURNAL OF BIOETHICS | Online – 21 March 2019 – Withholding and withdrawing treatment are widely regarded as ethically equivalent in medical guidelines and ethics literature. Healthcare personnel, however, widely perceive moral differences between withholding and withdrawing. The proponents of equivalence argue that any perceived difference can be explained in terms of cognitive biases and flawed reasoning. Thus, policymakers should clear away any resistance to accept the equivalence stance by moral education. To embark on such a campaign of changing attitudes, we need to be convinced that the ethical analysis is correct. Is it? The author takes a closer look at the moral relation between withholding and withdrawing. His conclusion is that withholding and withdrawing are not in general ethically equivalent. Thus, medical guidelines should be rewritten, and rather than being “educated” away from their sound judgments, medical professionals and patients should have nuanced medico-ethical

discussions regarding withholding and withdrawing treatment. **Abstract:** <http://bit.ly/2HOt6jE>

Publishing Matters

‘Making and measuring an impact in a digital world: The role of social media and the medical journal’ (p.16), in *Journal of the American Geriatrics Society*.

‘Potential predatory journals are colonizing the International Committee of Medical Journal Editors recommendations list of followers’ (p.16), in *The Netherlands Journal of Medicine*.

‘No free lunch: What price Plan S for scientific publishing?’ (p.17), in *New England Journal of Medicine*.

‘Time to say goodbye to “statistically significant” and embrace uncertainty, say statisticians’ (p.17), posted on the Retraction Watch website.

N.B. There are several articles on the issue of withholding and withdrawing life-sustaining treatment in this issue of the *American Journal of Bioethics*. **Journal contents page:** <http://bit.ly/2ToM4zI>

End-of-life care in the U.S.

Medicare cost at end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 18 March 2019 – As the Medicare program struggles to control expenditures, there is increased focus on opportunities to manage patient populations more efficiently and at a lower cost. A major source of expense for the Medicare program is beneficiaries at end of life (EoL). Estimates of the percentage of Medicare costs that arise from patients in the last year of life differ, ranging from 13% to 25%, depending on methods and assumptions. The authors analyze the most recently available Medicare Limited Data Set to update prior studies of EoL costs and examine different methods of performing this calculation. Based upon these findings, they conclude that higher estimates that take into account the spending over the 12 months leading up to death more accurately reflect the full cost of a patient’s last year of life. Comparing current year costs of decedents with Medicare’s current year costs understates the full budgetary impact of EoL patients. Because risk-taking entities such as Medicare Advantage plans and Accountable Care Organizations (ACOs) need to reduce costs while improving the quality of care, they should initiate programs to better manage the care of patients with serious or advanced illness. The authors also calculate costs for beneficiaries dying in different settings and conclude that more effective use of palliative care and hospice benefits offers a lower cost, higher quality alternative for patients at EoL. **Abstract:** <http://bit.ly/2TLC08p>

Ethical failings of College of Physicians & Surgeons of Ontario policy and the Health Care Consent Act: Case review

BMC MEDICAL ETHICS | Online – 20 March 2019 – End-of-life disputes in Ontario are currently overwhelmingly assessed through the singular lens of patient autonomy. The current dispute resolution mechanism(s) does not adequately consider evidence-based medical guidelines, standards of care, the patient's best interests, expert opinion, or distributive justice. The authors discuss two cases adjudicated by the Consent & Capacity Board of Ontario that demonstrate the over emphasis on patient autonomy. Current healthcare policy and the Health Care Consent Act also place emphasis on patient autonomy without considering other ethically defensible factors. The authors argue that current policy and legislation require amendment, and unless there are measures undertaken to modify them, both the quality of care provided and the long-term capabilities of the healthcare system to remain publicly-funded, comprehensive and equitable, are at stake. **Full text:** <http://bit.ly/2FmQF12>

N.B. 'Planning for and Providing Quality End-of-Life Care,' College of Physicians & Surgeons of Ontario (**Download/view at:** <http://bit.ly/2HJ7Ewn>); Ontario Health Care Consent Act (**Download/view at:** <http://bit.ly/2HHcJoR>); Consent & Capacity Board of Ontario website: <http://bit.ly/2Fp9ikU>.

Advance directives in France: Do junior general practitioners want to improve their implementation and usage? A nationwide survey

BMC MEDICAL ETHICS | Online – 18 March 2019 – A small percentage of responders would “systematically take advance directives (AD) into account.” Such a decision could be questionable considering that according to the 2005 French law, physician should have taken AD into account. The survey was not designed to explain such observations, but we already know that until the modification of the ethical law in France (2016) many doctors considered that patients were not competent to decide what level of therapeutic intensity they should receive and affirm they would not apply these AD arguing of the impossibility to be sure the patient did not have change his/her mind since the AD were wrote, or considering the patient unable to take an “informed decision” due to the lack of information concerning ICU or surgery, etc. On the other hand, many clinicians were much more afraid of legal consequences of a therapeutic withdrawal or withholding than of an excess in intensity of care. Moreover, despite large modification in the current law, weaknesses remain leading French physician to keep some distance from AD. In emergency situation, “stabilization of the patient condition” could (and probably should) be done before taking AD into account, at least in case of uncertainty about patient status. Many semantic points remain unanswered, for example: AD are often considered as wished for “end of life” situation, but except for chronic diseases, this notion is far unclear leading to an excess of aggressive treatment of severe conditions even in case of DNR wishes of the patient; another example could be the notion of “refusal of therapeutic relentlessness” which does not mean anything, leaving the clinician to choose when the treatment becomes futile. These points of weakness of the law, this supposed difference between the text and spirit of the law and the fear of not doing enough (in curative cares) are favoring intensity instead of comfort care in many situations. **Full text:** <http://bit.ly/2YgBzSq>

Specialist palliative care support is associated with improved pain relief at home during the last 3 months of life in patients with advanced disease: Analysis of 5-year data from the national survey of bereaved people (VOICES)

BMC MEDICINE | Online – 22 March 2019 – The authors' analysis of 43,509 patients who were cared for at home before death showed that receiving specialist palliative care (SPC) and have a recorded preference for place of death were found to be strongly and independently associated with good pain relief in the last 3 months of life. These findings have contributed to evidence supporting the need for, and the benefits of, SPC and recording preferences for place of death for patients with advanced disease. Furthermore, the authors demonstrate that respondents who were spouses or partners of the decedents were much more likely to report better pain relief than respondents who were sons or daughters. A major

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strength of this study is that data from the first national survey on the quality of end-of-life (EoL) care in England was used. However, the study has a number of limitations. A key drawback is that it was an analysis of a post-bereavement survey which used the perceptions of decedent's relatives as proxy measure of the quality of care experienced by the patient. Retrospective ratings of EoL care by decedent's relatives could be different from the actual experience of the decedent. Research is difficult to conduct on patients with advanced progressive disease and although the validity and reliability of proxies are questionable, it may need to be accepted and utilised as a valuable part of EoL research. Without this proxy measure, there are only few, poorly powered studies to inform important policy documents and the practice of EoL care. **Full text:** <http://bit.ly/2HBMoZV>

Barriers to use of palliative care and advance care planning discussions for patients with end-stage liver disease

CLINICAL GASTROENTEROLOGY & HEPATOLOGY | Online – 15 March 2019 – Despite evidence for the benefits of palliative care (PC) referrals and early advance care planning (ACP) discussions for patients with chronic diseases, patients with end-stage liver disease (ESLD) often do not receive such care. The authors conducted a cross-sectional survey of hepatologists and gastroenterologists who provide care to adult patients with ESLD, recruited from the American Association for the Study of Liver Diseases 2018 membership registry. The most commonly cited barriers to PC use were cultural factors that affect perception of PC (by 95% of respondents), unrealistic expectations from patients about their prognosis (by 93% of respondents), and competing demands for clinicians' time (by 91% of respondents). Most respondents (81%) thought that ACP discussions with patients who have ESLD typically occur too late in the course of illness. **Abstract:** <http://bit.ly/2HrBp5i>

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

- *LIVER TRANSPLANTATION* | Online – 13 February 2019 – **'Current knowledge, barriers to implementation, and future directions in palliative care for end-stage liver disease.'** End-stage liver disease (ESLD) is increasing in incidence, resulting in a greater burden on the healthcare system, which is estimated to cost [in the U.S.] over \$2 billion each year. Unfortunately, many of these expenditures fail to meaningfully improve or prolong life for patients. In addition to these costs, patients with ESLD suffer a high burden of symptoms and invasive procedures, even when death may be imminent. **Abstract:** <http://bit.ly/2UWqinN>

Noted In Media Watch 26 November 2018 (#591, p.15):

- *THE LANCET GASTROENTEROLOGY & HEPATOLOGY* | Online – 21 November 2018 – **'Unmet needs in end-of-life care for chronic liver disease.'** Liver disease mortality increased by 400% in the U.K. between 1970 and 2010, resulting in rising pressures on acute hospital services and an increasing need for end-of-life care. Alcohol-related liver disease has been responsible for at least two in every five deaths over the past two decades. Corresponding to increased rates of obesity, the proportion of chronic liver disease-related deaths due to non-alcoholic fatty liver disease has doubled over the past decade. **Abstract (w. list of references):** <http://bit.ly/2tpQjQo>

Prescription and deprescription of medications for older adults receiving palliative care during the last 3 months of life: A single-center retrospective cohort study [in France]

EUROPEAN GERIATRIC MEDICINE | Online – 15 March 2019 – This study highlights the preferential prescription of essential drugs and deprescription of unnecessary drugs during the last 3 months of life in older adults. However, palliative care (PC) occurs principally during the last week of life and a high burden of unnecessary drugs is still found on the day of death. Both earlier implementation of PC and an improvement of prescribing practices are needed by setting up interventions to raise awareness and promote early physician-patient communication about care goals and potential benefits of deprescribing unnecessary drugs. **Abstract (w. list of references):** <http://bit.ly/2Y5JySb>

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

End-of-life care in the U.S.

How we use hospice: Hospice enrollment patterns and costs in elderly ovarian cancer patients

GYNECOLOGIC ONCOLOGY, 2019;152(3):452-458. The authors describe disparities in patterns of hospice use and end-of-life costs among ovarian cancer patients. 2,331 patients were assessed: 1,788 (77%) white, 359 (15%) Hispanic, 158 (7%) black and 26 (1%) other. 1,756 (75%) enrolled in hospice prior to death, but only 1,580 (68%) died with hospice. 176 (10%) of 1,756 patients unenrolled and died without hospice. 346 (20%) unenrolled from hospice multiple times. From 2008 to 2012, patients were less likely to unenroll from hospice prior to death. Black patients were more likely to unenroll from hospice prior to death compared to white patients. The median amount paid by Medicare during the last six months of life was \$38,530 for those in hospice compared to \$49,942 if never enrolled in hospice and was higher for black and Hispanic patients compared to white patients. 30% hospice unenrolled patients and 40% multiply enrolled hospice patients received at least one life extending or invasive care procedure following unenrollment from hospice. **Abstract (inc. link to references):** <http://bit.ly/2W6NIYe>

Noted in Media Watch 4 February 2019 (#600, p.14):

- *OBSTETRICS & GYNECOLOGY CLINICS OF NORTH AMERICA*, 2019;46(1):179-197. '**Palliative care in gynecologic oncology.**' The integration of palliative care (PC) and hospice into standard gynecologic oncology care is associated with cost-savings, longer survival, lower symptom burden, and better quality of life for patients and caregivers. Consequently, this comprehensive approach is formally recognized and endorsed by the Society of Gynecologic Oncology, the National Comprehensive Cancer Network, and the American Society of Clinical Oncology. This article reviews the background, benefits, barriers, and most practical delivery models of PC. It also discusses management of common symptoms experienced by gynecologic oncology patients. **First page view:** <http://bit.ly/2G4Q5Gd>

Noted in Media Watch 20 August 2018 (#577, p.9):

- *GYNECOLOGIC & OBSTETRIC INVESTIGATION* | Online – 10 August 2018 – '**Gynecologic oncologists' perceptions of palliative care and associated barriers: A survey of the Society of Gynecologic Oncology.**' A total of 174 (16%) gynecologic oncologists [i.e., members of the Society] completed the survey. The majority (75%) agreed or strongly agreed that palliative care (PC) should be integrated into cancer care at diagnosis of advanced or metastatic cancer. The most frequently perceived PC barriers included patients' unrealistic expectations (54%), limited access to specialty PC (25%), poor reimbursement (25%), time constraints (22%), and concern of reducing hope or trust (21%). **Abstract (w. list of references):** <http://bit.ly/2RUZR4L>

Cardiopulmonary resuscitation, informed consent, and rescue: What provides moral justification for the provision of CPR?

JOURNAL OF CLINICAL ETHICS, 2019;30(1):67-73. Questions related to end-of-life decision making are common in clinical ethics and may be exceedingly difficult. Chief among these are the provision of cardiopulmonary resuscitation (CPR) and do-not-resuscitate orders (DNRs). To better address such questions, clarity is needed on the values of medical ethics that underlie CPR and the relevant moral framework for making treatment decisions. An informed consent model is insufficient to provide justification for CPR. Instead, ethical justification for CPR rests on the rule of rescue and on substituted interest judgments. Patients' known wishes and values are relevant, particularly in protecting them from unwanted CPR. Clinicians should rescue patients with the means at their disposal, as a *prima facie* moral imperative, unless there are compelling reasons to refrain. The authors present a moral framework for making decisions regarding CPR and DNR. **Abstract:** <http://bit.ly/2FpPSLx>



Would this article be of interest to a colleague?

“Juggling amidst complexity”

Hospice staff’s experience of providing palliative care for infants referred from a neonatal unit

JOURNAL OF NEONATAL NURSING | Online – 11 March 2019 – Hospice has been pivotal to children’s palliative care (PC) provision in the U.K. for more than 3 decades. Some hospices have recently expanded to include care of infants transferred from neonatal units as well as antenatal referrals. Despite developments, evidence suggests hospice care is often not offered to parents in neonatal units. This study examines perspectives of 17 staff from 3 children’s hospices regarding the challenges and opportunities caring for infants in hospice. Data was collected from 3 focus groups and analysed using a thematic approach. Findings suggest that hospice staff juggle many complex issues when caring for infants at the end-of-life. Such issues centre round the referral process from hospital services borne from an apparent reluctance of hospital staff to let go, through involving hospice. Education, partnership working, planning for all possible outcomes seems crucial in further developing quality PC for infants and their families. **Abstract:** <http://bit.ly/2Cz6a4v>

Noted in Media Watch 12 November 2018 (#589, p.5):

- *ADVANCES IN NEONATAL CARE* | Online – 31 October 2018 – ‘**The best interests of infants and families during palliative care at the end of life: A review of the literature.**’ This article examines what neonatal palliative care entails, how parents perceive healthcare providers’ actions, what they potentially need at the end of their infant’s life, and what bereavement interventions are most supportive for parents. Healthcare providers should consider alleviation of the infant’s pain and suffering when discussing whether to provide or continue aggressive medical interventions. The timing of these discussions is important. Furthermore, the infant’s quality of life must be considered when discussing withholding or withdrawing care. **Abstract:** <http://bit.ly/2u8Ntjo>

The limits of “life-limiting”

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 March 2019 – The field of hospice and palliative medicine has struggled to define the conditions which are appropriate for palliative care (PC). “Life-threatening” appropriately encompasses lethal conditions and helpfully incorporates the concept of probability, which is a necessary variable in any risk calculation. Yet it leaves one important group of patients unaccounted for: those whose primary need for PC is not expected abbreviation of life but rather the quality of that life. In an attempt to include these patients, the term “life-limiting” has come to be used more frequently. While attractive in its breadth – and at first glance appearing to be a less threatening way to introduce PC – the term is inherently flawed. It denotes a certain outcome, without any consideration of the likelihood of that outcome. Rather than “softening the blow” of introducing PC, the term seems to condemn a patient to the very outcome that PC is tasked to ameliorate, namely, the limitation of life. As such, it may provide a distorted view of what PC is, especially in pediatrics where the term is used with disproportionate frequency. The inherent misplaced certainty of “life-limiting” and the self-defeating message it sends to patients should be acknowledged. **Abstract (inc. link to references):** <http://bit.ly/2HJT6we>

Legacy artwork in pediatric oncology: The impact on bereaved caregivers’ psychological functioning and grief

JOURNAL OF PALLIATIVE MEDICINE | Online – 20 March 2019 – Legacy-making (i.e., a way for patients with terminal illness to create or do something for others as a means of remembrance) is rising in popularity in palliative medicine, although only one study has examined its impact in a pediatric population. Forty-four caregivers whose children died of cancer completed a demographic questionnaire specifically created for this study, the Brief Symptom Inventory-18, and the Prolonged Grief Disorder-13. They also answered questions regarding supportive services provided to them toward the end of the child’s life, at the time of death, and after the child’s death. Those caregivers who endorsed participating in legacy

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artwork were identified as the intervention group, whereas those who did not were classified as the control group. There were no significant differences in psychological functioning among caregivers who participated in legacy artwork versus those who did not participate. However, caregivers who created legacy artwork with their child reported significantly less symptoms of prolonged grief and a greater perception of support from health care providers compared with caregivers who did not engage in this activity. Although preliminary, these findings suggest that legacy artwork may have the potential to improve grief and overall satisfaction of support from the hospital in bereaved caregivers. **Abstract:** <http://bit.ly/2UMee95>

Results of a nationwide hospice and palliative care social work job analysis

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 20 March 2019 – The role of the hospice and palliative social worker is often ambiguous and misunderstood by colleagues and fellow team members. One reason for this is the lack of identified, clearly delineated roles, skills, and tasks employed by these specialty social workers in their daily work. This article summarizes the first nationwide job analysis of hospice and palliative social workers. A sample of 482 social workers representing 46 states [in the U.S.] responded to a survey that included demographic questions and ranking of 152 tasks and importance to the position. Tasks were categorized into four broad categories: 1) Assessment and re-evaluation; 2) Planning and intervention; 3) Death, grief, and bereavement; and, 4) Professionalism; which included sub-categories consisting of multiple tasks and skills. Respondents identified performing a psychosocial assessment from a patient/family centered care perspective, assessment of the patient's current and desired quality of life and of coping skills as the tasks most important to their role. This outline of the role of the hospice and palliative social worker was then used in the development of an evidence-based certification exam

that may be required of those who want to receive specialty certification in the field. **Abstract:** <http://bit.ly/2WhBkET>

Sitting with silence: Hospital social work interventions for dying patients and their families

SOCIAL WORK IN HEALTH CARE | Online – 19 March 2019 – The recent controversy around the hospital end of life (EoL) care has highlighted the vulnerability of dying patients and their families. However, little is known about how social workers provide support and intervention around the EoL in the hospital. Eight hospital social workers provided qualitative descriptions of their clinical practice for adult patients and their families. Highlighting a theoretical orientation towards a person-in-environment approach, social workers develop unique interventions to contribute to multidisciplinary care. Findings emphasize the need to prepare social work students and clinicians for the reality of working with EoL issues. **Abstract:** <http://bit.ly/2Y9jcyC>

N.B. Additional articles on silence as an element of care noted in 28 January 2019 issue of Media Watch (#599, p.15).

Related

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 20 March 2019 – **'Educating our future colleagues: Creating an MSW palliative care practicum.'** As the number of older adults and those with chronic medical conditions continues to rise, the need to train social work students in palliative and end-of-life competencies becomes critical. The social work team at a large urban academic medical center in the Midwest developed an MSW concentration practicum in palliative and end-of-life care. This article describes the curriculum, practice immersion, training manual, teaching modules, and structure of student supervision... **Abstract:** <http://bit.ly/2FuxW3O>

Noted In Media Watch 18 March 2019 (#606, p.9):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 11 March 2019 – **'The end of life within social work literature: A conceptual review.'** An iterative content analysis of included articles revealed six themes within reported definitions and four themes within eligibility criteria. Definitions related to treatment responsiveness, the death process, dying, prognosis, admission to specific services, and old age. Eligibility criteria related to proxy assessment, diagnosis, prognosis, and functional ability assessments. Over one-third of included articles did not define what was meant by the end of life and the majority did not include eligibility criteria. **Abstract:** <http://bit.ly/2UwPykN>

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Noted in Media Watch 11 February 2019 (#601, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 4 February 2019 – ‘**What are social work student being taught about palliative care?**’ Of the 105 participating programs that responded to a survey, 42 submitted 70 syllabi for courses with at least some palliative care (PC) content. The most common topics were grief, loss and bereavement; behavioral and mental health issues; supporting family and friends; cultural perspectives; and, advance care planning. Although there are many challenges, including unqualified faculty and competing course material and electives of equally compelling content, there are model curricula for dedicated PC courses. **Abstract:** <http://bit.ly/2WGacAI>

Service delivery models to maximize quality of life for older people at the end of life: A rapid review

THE MILBANK QUARTERLY | Online – 18 March 2019 – The authors identified two overarching classifications of integrated geriatric and palliative care (PC) to maximize older people’s quality of life at the end of life (EoL). Both are oriented to person-centered care, but with differing emphasis on either function or symptoms and concerns. Policymakers should both improve access to PC beyond just the last months of life and increase geriatric care provision to maintain and optimize function. This would ensure that continuity and coordination for potentially complex care needs across the continuum of late life would be maintained, where the demarcation of boundaries between healthy aging and healthy dying become increasingly blurred. The findings of this study highlight the urgent need for health system change to improve EoL care as part of universal health coverage. The use of health services should be informed by the likelihood of benefits and intended outcomes rather than on prognosis. **Full text:** <http://bit.ly/2FIZo3w>

A scoping review of palliative care for persons with severe persistent mental illness

PALLIATIVE & SUPPORTIVE CARE | Online – 19 March 2019 – People with severe persistent mental illness (SPMI) experience a greater burden and severity of chronic disease, late diagnosis, and premature death compared with the general population. This systematic scoping review reveals a highly vulnerable population with complex needs that are not reliably being met by the healthcare system and providers. Research in this area must continue to develop using rigorous qualitative and quantitative study designs, and interventions should be developed and tested based on existing knowledge to inform care. The voices of people with severe persistent mental illness (SPMI) in need of palliative care (PC) must be represented in future studies to address gaps. To expand a body of literature addressing mainly individuals, system perspectives and socio-cultural analysis can bring much to contextualizing the experience of living with SPMI in the palliative phase of care. Adoption of a palliative approach, which promotes the principles of PC across non-specialized care settings provided by non-specialist palliative providers, has the potential to increase access to high-quality palliative treatment for people with SPMI. **Abstract (w. list of references):** <http://bit.ly/2TVvgnN>

Close-person spill-overs in end-of-life care: Using hierarchical mapping to identify whose outcomes to include in economic evaluations

PHARMACOECONOMICS | Online – 15 March 2019 – Guidelines for economic evaluations often request that costs and outcomes beyond the patient are captured; this can include carers and also other affected parties. End-of-life (EoL) care is one context where impacts of care spill over onto those other than patients, but there is little evidence about who should be included within economic evaluations. The purpose of this article was to examine: 1) How many people are close to those at the EoL; 2) Their characteristics; and, 3) What influences the network size at the EoL. In-depth interviews were conducted with 23 participants who were either recently bereaved or had somebody close to them currently receiving EoL care. On average, close-person networks at the EoL contained eight individuals, three of whom were rated as being “closest.” These were typically family members, although in a small number of cases non-family members were included amongst the closest individuals. There was variation in terms of network composition. Qualitative analyses revealed two key influences on network size: death trajectory (those with cognitive problems/diseases towards the EoL had smaller networks) and family size (larger families had larger networks). **Abstract (w. list of references):** <http://bit.ly/2UAXy90>

Using business/law negotiation techniques in response to a “difficult” family

PROGRESS IN PALLIATIVE CARE | Online – 18 March 2019 – Effective communication between clinicians, patients, and families at end of life is associated with better clinical outcomes. A large body of literature describes the key skills needed for effective communication. The authors believe that clinicians could also benefit from communication skills more commonly associated with business or law negotiations. They demonstrate via analogy (i.e. buying a house) how four key business/law negotiation techniques – 1) Determine your reservation and aspiration value; 2) Separate people from their positions; 3) Separate positions from interests; and, 4) Logrolling of interests – can be applied to a difficult family meeting in a home hospice patient. **Abstract:** <http://bit.ly/2W9fsv6>

Communication of emotion in home hospice cancer care: Implications for spouse caregiver depression into bereavement

PSYCHO-ONCOLOGY | Online – 18 March 2019 – This study included hospice nurses and family caregivers of cancer patients recruited from 10 hospice agencies in the U.S. Caregivers had moderate levels of depression at study enrollment and throughout bereavement. This is the first study to demonstrate that communication demonstrating emotional expression between cancer spouse caregivers and nurses during home hospice may have implications for caregiver depression up to a year after patient death. The authors' findings may help identify caregivers who may be coping well in the short term, but may struggle more over time. **Abstract:** <http://bit.ly/2ujMqgl>

Prognostication in advanced cancer: Update and directions for future research

SUPPORTIVE CARE IN CANCER | Online – 13 March 2019 – The most common prognostic approach is clinician prediction of survival (CPS) using temporal, surprise, or probabilistic questions. The surprise and probabilistic questions may be more accurate than the temporal approach, partly by limiting the time frame of prediction. Prognostic models such as the Glasgow Prognostic Score, Palliative Performance Scale, Palliative Prognostic Score, Palliative Prognostic Index, or Prognosis in Palliative Care Study predictor model may augment CPS. However, care must be taken to select the appropriate tool since prognostic accuracy varies by patient population, setting, and time frame of prediction. In addition to life expectancy, patients and caregivers often desire that expected treatment outcomes and bodily changes be communicated to them in a sensible manner at an appropriate time. The authors propose ten major themes for future prognostication research: 1) Enhancing prognostic accuracy; 2) Improving reliability and reproducibility of prognosis; 3) Identifying the appropriate prognostic tool for a given setting; 4) Predicting the risks and benefits of cancer therapies; 5) Predicting survival for pediatric populations; 6) Translating prognostic knowledge into practice; 7) Understanding the impact of prognostic uncertainty; 8) Communicating prognosis; 9) Clarifying outcomes associated with delivery of prognostic information; and, 10) Standardizing prognostic terminology. **Abstract (w. list of references):** <http://bit.ly/2UFe8Qv>

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[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2019;57(2):233-240. '**Palliative care clinician overestimation of survival in advanced cancer: Disparities and association with end-of-life care.**' This is a multi-site study of 230 hospitalized patients who consulted with palliative care (PC)... The authors asked the consulting PC clinician to make their "best guess" about the patients' "most likely survival time, assuming that their illnesses are allowed to take their natural course." 41% of clinicians' predictions were accurate. Among inaccurate prognoses, 85% were overestimates. Overestimation is common in PC, associated with lower hospice use and a potentially mutable source of racial/ethnic disparity in end-of-life care. **Abstract (inc. link to references):** <http://bit.ly/2HrKtav>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *MORTALITY* | Online – 21 March 2019 – '**Determining the end of life: A qualitative study of religion and euthanasia among older Dutch adults.**' In Dutch discourses euthanasia has consecutively been viewed as murder, as mercy offered by medical doctors, and as a self-chosen right for older people. This seems to reflect decreasing religious authority over death. Twenty-six interviews with Dutch adults aged 79-100 were carried out to evaluate the relationship between religion and attitudes towards euthanasia. Qualitative analysis indicates three groups of participants. Participants in the refraining group, wishing not to let the moment of their death be determined by euthanasia, predominantly believed both in God and an afterlife, and had most preference for a religious funeral. Participants in the depending group, wishing to ground euthanasia decisions in medical criteria, were least religious, which illustrates the co-occurrence of medicalisation and secularisation of death. Participants in the self-determining group, asserting that older adults should be allowed to determine themselves if and when they wish to receive euthanasia, were almost as religious as the refraining group, although they believed less in an afterlife. Their less traditional religiosity suggests that the late modern decline of traditional religious frameworks affords both self-determination concerning euthanasia and individual interpretations of religiosity. Moreover, the authors' data suggest a connection between a persistent death wish in older adults and a perceived social death. **Full text:** <http://bit.ly/2TTx9SW>
- *PALLIATIVE & SUPPORTIVE CARE* | Online – 19 March 2019 – '**Improving the medical assistance in dying (MAiD) process: A qualitative study of family caregiver perspectives.**' This study used structured surveys, focus groups, and unstructured e-mail/phone conversations to gather experiential feedback from family caregivers (FCGs) of patients who underwent medical assistance in dying (MAiD) ... at a large academic hospital in Toronto, Canada. Improvement themes identified ... were grouped in two categories: operational and experiential aspects of MAiD. Operational themes included: process clarity, scheduling challenges and the 10-day period of reflection. Experiential themes included clinician objection/judgment, patient and family privacy, and bereavement resources. To the authors' knowledge, this is the first time that FCGs' perspectives on the quality of the MAiD process have been explored. Although practice standards have been made available to ensure all legislated components of the MAiD process are completed, detailed guidance for how to best implement patient and family centered MAiD programs at the institutional level remain limited. This study provides guidance for ways in which we can enhance the quality of MAiD from the perspective of FCGs. **Abstract (w. list of references):** <http://bit.ly/2FdWb4Z>
- *UNIVERSITY OF TORONTO LAW JOURNAL* | Online – 19 March 2018 – '**Assisted dying, suspended declarations, and dialogue's time.**' How long does it take the elected branches of government to study complex policy questions and develop legislation that respects constitutional rights? Judges often suspend for 12 months declarations that a law unjustifiably limits a right protected by the Canadian Charter of Rights & Freedoms. Dialogue theorists praise such suspensions for allowing the legislative and executive branches to act. The paper recounts the experiences of the governments of Quebec and of Canada in grappling with assisted suicide en route to legislating. It concludes that tackling a serious policy issue – including research, public education and consultation, and meaningful deliberation – may take much longer than 12 months. Consequent possible changes to judicial practice include granting fewer suspensions and prompting fuller debate in court on the appropriate order. As for dialogue theorists, they might better align their justifications of suspensions with legislative realities. **Abstract:** <http://bit.ly/2JvQuEH>

Publishing Matters

Making and measuring an impact in a digital world: The role of social media and the medical journal

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY (JAGS) | Online – 15 March 2019 – In 1953, *JAGS* published its inaugural issue to fill a void in journals publishing on issues of aging. That same year, life science and biomedical researchers published 49,645 English-language articles now referenced in PubMed. Over the intervening years, the number of articles published and referenced in PubMed has grown dramatically, with over 1.2 million referenced in 2018 alone. For any article to have a significant impact and not be lost in the cacophony of academic publications, traditional ways of disseminating the findings of research articles need to evolve. Social media platforms, such as Twitter and Facebook, provide new ways for medical journals and researchers to disseminate the findings of published articles to a broader audience than the usual journal-subscriber base. They also are shifting the ways audiences act upon those findings. A 2015 report released from the Congressional Management Foundation, for example, found that as few as 30 social media

posts on an issue would force Congressional staffers to “pay attention” to the concern, with 70% of staffers also noting that platforms like Twitter and Facebook made legislators “more accountable” to their constituents.¹ *JAGS* began promoting articles via multiple online platforms in 2016 through a targeted social media strategy. In addition to Facebook, Twitter, and LinkedIn posts from the journal accounts, *JAGS* collaborates with a geriatrics and palliative care podcast and has had articles featured in an online geriatrics journal club. **Full text:** <http://bit.ly/2TgkeoS>

Extract from *JAGS* article

Social media platforms, such as Twitter and Facebook, provide new ways for medical journals and researchers to disseminate the findings of published articles to a broader audience than the usual journal-subscriber base. They also are shifting the ways audiences act upon those findings.

1. ‘Report – #Social Congress 2015,’ Congressional Management Foundation, Washington DC. **Download/view at:** <http://bit.ly/2TJEsfn>

Potential predatory journals are colonizing the International Committee of Medical Journal Editors recommendations list of followers

THE NETHERLANDS JOURNAL OF MEDICINE, 2019,77(2):92-96. The International Committee of Medical Journal Editors (ICMJE) has expressed its concerns about predatory journals using the list of ICMJE Recommendations (ICMJE-R) followers to “gain the appearance of legitimacy.” The authors assessed the presence of potential predatory journals on the ICMJE-R list and their adherence to ICMJE recommendations. A random sample of 350 journals from the estimated 3,100-3,200 biomedical journals listed as ICMJE-R followers was chosen. Data collected from the ICMJE and journal web pages in English were: adherence to six ICMJE-R policies/requirements, year of journal’s listing as ICMJE-R follower, discipline covered, publisher and its country of origin and existence of article processing charge. Potential predatory journal was considered as one open access journal not being a member of a recognized listing in Committee of Publication Ethics, Directory of Open Access Journals, Open Access Scholarly Publishers’ Association, African Journals Online and/or International Network for the Availability of Scientific Publications. Thirty-one percent of journals were considered to be potentially predatory; 94% of them were included in the ICMJE-R list in 2014-2018. Half were published in the U.S. and 62% were devoted to medicine. Adherence to five of the six policies/requirements was infrequent, ranging from 51% (plagiarism) to 7% (trial registration). Seventy-two percent of journals mentioned a policy on authors’ con-



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flicts of interest. Information on article processing charge was available for 76% journals and could not be found for 22%. Authorship policy/ instructions were significantly more present in journals with publishers from India than from the U.S..., with no differences in the other five policies. Predatory journals should be deleted from the ICMJE-R list of followers to prevent misleading authors. ICMJE-R following journals need to be re-evaluated with pre-defined published criteria. **Abstract:** <http://bit.ly/2HMWmqK>

No free lunch: What price Plan S for scientific publishing?

THE NEW ENGLAND JOURNAL OF MEDICINE, 2019;380 (12):1181-1185. The idea ... that the results of research should be available to be read, discuss, and examine, so that flawed results can be rejected and new scientific discoveries be made on the basis of sound evidence ... has few, if any, opponents in either the scientific community or the public. Nor is there any disagreement over the fact that the Internet has profoundly and permanently changed the ways in which information can be disseminated and discussed and has therefore changed scientific publishing considerably. All forms of publications are more publicly accessible today than they were 20 years ago. But the open access movement developed not only because of the new opportunities provided by the Internet for dissemination of science, but also because of frustration over rising subscription costs – and profit margins – of traditional journals and publishing houses. Librarians felt caught in a bind because researchers who had published in journals, peer reviewed for them, and maybe even served on their editorial boards naturally wanted access to those journals in their institutional libraries. When subscription costs became too high, the

blame was placed on the traditional business model of scientific publishing, which was seen as restricting access to science. New business models in which authors or funders paid for publication instead of readers or institutions paying subscription fees, and in which there was an open approach to copyright so that both reading and unrestricted reuse of the content were free, were necessary for the advancement of science. This model — now called “Gold Open Access” — would also drive costs down: “The significantly lower overall cost of dissemination is a reason to be confident that the goal is attainable and not merely preferable or utopian.” **Full Text:** <http://bit.ly/2U4oOLp>

Plan S principles

After 1 January 2020 scientific publications on the results from research funded by public grants provided by national and European research councils and funding bodies, must be published in compliant open access journals or on compliant open access platforms.

Time to say goodbye to “statistically significant” and embrace uncertainty, say statisticians

RETRACTION WATCH | Online – 21 March 2019 – Three years ago, the American Statistical Association (ASA) expressed hope that the world would move to a “post-p-value era.” The statement in which they made that recommendation has been cited more than 1,700 times and, apparently, the organization has decided that era’s time has come. (At least one journal had already banned p values by 2016.) In an editorial in a special issue of *The American Statistician*¹ ... the executive director of the ASA, Ron Wasserstein, along with two co-authors, recommends that when it comes to the term “statistically significant,” “don’t say it and don’t use it.” (More than 800 researchers signed onto a piece published in *Nature* ... calling for the same thing.²) <http://bit.ly/2Cvsnjw>



1. 'Moving to a world beyond “ $p < 0.05$,”’ *The American Statistician*, published online 20 March 2019. **Full text:** <http://bit.ly/2Hx9Ojd>
2. 'Scientists rise up against statistical significance,' *Nature*, published online 20 March 2019. **Full text:** <https://go.nature.com/2TkvPU0>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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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International



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PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2G2igko>

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

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

[Scroll down to 'Are you aware of Media Watch?']

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

Europe



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

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

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

South America

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

United States

NEBRASKA | Center for Health Policy & Ethics, Creighton University: <http://bit.ly/2DAED3f>

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