

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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Failure to plan for adequate palliative and hospice care when a substantial increase in disease and death is expected is unconscionable, and it risks undermining patient-family trust, long-term emotional health, and the core values of society.

'Ensuring adequate palliative and hospice care during COVID-19 surges' (p.10),
in *Journal of the American Medical Association*.

Canada

Palliative vs. supportive: The zombie argument that refuses to die

HEALTHY DEBATE | Online – 23 September 2020 – [In this article, the author refers to] ... the persistent argument that we need to change the name of palliative care (PC) to “supportive care.” The argument is that PC is associated with death and dying and that for this reason, allegedly, access to high-quality PC remains poor. It has been suggested that patients and clinicians avoid using the term “palliative,” which in turn leads to patients not being referred to PC services in a timely fashion. This argument, long felt to be settled, was raised again in a recent *Washington Post* article...¹ The article starts by stating that the very phrase “palliative care” is frightening to many people with critical illness and that “a growing movement is advocating to rename PC.” PC has been shown to significantly improve a patient’s quality of life, decrease stress and burden on families and caregivers while, in some cases, actually increasing a patient’s survival. These benefits have been shown in both cancer and non-cancer patients. Not so frightening. Interestingly enough, like a shambolic zombie, the *Washington Post* article actually debunks itself when it states “that over 70% of respondents didn’t even know what PC was.” Further, the article goes on to clarify that “of those who were aware of PC, almost two-thirds think it is the same as hospice.” While the article aims to increase the “acceptability of PC for both patients and clinicians,” it fails to make a case that it is the name that is the actual barrier. The reasons for poor access to PC in Canada are not rooted in nomenclature but rather in the priorities of our healthcare system. For decades, we have collectively valued cure over care, technology over compassion and innovation over simply “being present.” This is not to discount the former but it is telling that we have ignored the latter to our detriment. The benefits of PC are undeniable, the evidence irrefutable. <https://bit.ly/3kF4vxK>

1. 'In pandemic era, the term palliative care is even more scary for some. So specialists want to rename it,' *The Washington Post*, 7 September 2020. [Noted in Media Watch 14 September 2020 (#683, p.3)] <https://wapo.st/3bydFJ7>

N.B. Selected articles on public awareness, knowledge and perceptions of hospice and PC noted in this issue of Media Watch.

U.S.A.

More than 60 organizations call for Medicare palliative care demo

HOSPICE NEWS | Online – 24 September 2020 – The U.S. Department of Health & Human Services and congressional leaders have received letters with signatures from more than 60 healthcare and senior citizen advocacy groups calling for a demonstration to test a community-based palliative care (PC) benefit program within Medicare. U.S. Centers for Medicare & Medicaid Services (CMS) tests the viability and functionality of new payment models and other initiatives through demonstration projects. The Medicare Hospice Benefit began as a demonstration project several years before it was made permanent. CMS in 2021 will begin a demonstration project to test the inclusion of hospice in the value-based insurance design model, often called the Medicare Advantage carve-in. Hospices currently provide about 50% of the community-based PC in the U.S. While no standardized definition exists for “palliative care,” CMS defines the term as “patient and family-centered care that optimizes quality of life by anticipating, preventing, and

treating suffering. PC throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.” Community-based PC has been shown to generate significant savings in healthcare costs, reduce hospitalizations and emergency department visits and improve the for patients who suffer from serious or chronic illness. <https://bit.ly/3i2txFj>

Specialist Publications

‘How COVID-19 changed advance care planning: Insights from the West Virginia Center for End-of-Life Care’ (p.10), in *Journal of Pain & Symptom Management*.

‘Palliative space-time: Expanding and contracting geographies of U.S. healthcare’ (p.15), in *Social Science & Medicine*.

Hospices seek to bridge racial divides in access to care

STATE OF NEW YORK | *Hospice News* – 19 September 2020 – Hospice providers are increasingly strategizing to improve access to end-of-life care (EoLC) among historically underserved populations in African American, Hispanic and Native American communities. With ongoing civil unrest nationwide bringing racial inequity issues to the forefront in healthcare, many providers have worked to better understand the underlying issues for these disparities and demonstrate the value of hospice care to these communities at large. Racial disparities in utilization of hospice and palliative care persist, with Black and Hispanic populations less likely to receive a referral than White patients according to recent data from the U.S. Agency for Healthcare Research & Quality.¹ Advocates have called for providers to bridge divides of inequity and gain a deeper understanding of the underlying issues that present barriers to EoLC. Visiting Nurse Service of New York has launched Project HOPE to overcome demographic barriers to hospice care among African Americans and Hispanics in the Harlem and Bronx boroughs of the New York City. <https://bit.ly/32LYoRX>

1. ‘Trends and racial disparities of palliative care use among hospitalized patients with end stage kidney disease on dialysis,’ *Clinical Journal of American Society of Nephrology*, 2019;30(9):1687-1696. [Noted in Media Watch 12 August 2019 (#626, p.8)] **Full text:** <http://bit.ly/2UJ9lnQ>

N.B. Selected articles on disparities in the provision and delivery of hospice and palliative care for racial/ethnic minorities in the U.S. noted in Media Watch 7 September 2020 (#682, pp.7-9) and 31 August 2020 (#681, p.3).



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

More than words: North Carolina doctor draws comics to navigate tough medical issues

NORTH CAROLINA | *The News & Observer* (Raleigh) – 18 September 2020 – Dr. Nathan Gray does some of the most notoriously difficult work in the field of medicine. Gray specializes in palliative care at Duke University Hospital, helping support patients and their families as they navigate all of the daunting concerns that come with a serious illness, including end-of-life issues. It requires a very specific skill set – deep empathy and an ability to communicate complex, sometimes hard truths. This is even more crucial as the Coronavirus pandemic sparks concerns and fears about the unknown, and people are having emotionally taxing conversations they didn't expect to have. That's where Gray's second line of expertise comes in. Gray, a life-long artist and doodler, has developed a side specialty in comics – specifically, deeply empathetic comics that communicate those complex and hard truths. Gray's work fits into a relatively recent but rapidly expanding area of work known as graphic medicine, which refers to the use of graphic novels, comics and visual storytelling in medical education and patient care. In the broadest sense, it's about using images and words together to impart medical information. <https://bit.ly/3iNawYN>



International

Number of Melbourne families providing palliative care at home soars under Coronavirus lockdown

AUSTRALIA (Victoria) | ABC News (Melbourne) – 24 September 2020 – The COVID-19 pandemic has not only changed the way Victorians live, it has changed the way they are dying, with the number of families providing palliative care (PC) for loved ones at home almost doubling in some Melbourne suburbs over the past six months. The surge has led to greater stress in families already struggling with the ramifications of COVID-19 lockdown measures, and “immense” strain among PC support staff, who say they cannot meet all the needs of everyone requiring their help. More than 80,000 Australians require PC each year. Eastern Palliative Care said the percentage of its patients choosing to die at home in the outer-eastern suburbs of Melbourne had leapt from 48% prior to the pandemic to as high as 83% during some weeks since the city's first lockdown in March. <https://ab.co/3mMQb8c>

Specialist Publications

'A national survey of anaesthetists' preferences for their own end-of-life care' (p.7), in *British Journal of Anaesthesia*.

'National Children's Hospitals Bereavement Network standards for supporting families following the death of a child' (p.12), in *Nursing Children & Young People*.

'Palliative care in public policy: Results from a global survey' (p.13), in *Palliative Medicine Reports*.

Coronavirus: Third of hospices [in England] on brink of redundancies and service cuts ahead of “surge in demand”

U.K. (England) | ITV News (London) – 24 September 2020 – A third of all hospices in England are on the brink of making redundancies and cutting back services for end-of-life care (EoLC) as the Coronavirus pandemic continues to plunge the sector deeper into a funding crisis. ITV News has learned that 56 of England’s 169 hospices are at financial risk and are being forced to contemplate service cuts and redundancies, just as the sector prepares for a second wave of COVID-19. Hospice UK, the national charity for hospices and palliative care, is working with National Health Service England to identify the most cash-strapped providers of EoLC to see if local clinical commissioning groups can step in to help. “Hospices still need to pay their nurses, but we’re seeing a third of hospices in England talking about making redundancies and cutting services and they will be permanent – which is catastrophic,” said Hospice UK. The cuts could come at a time when hospices are most needed to deal with a second wave of Coronavirus. In April, at the height of the first wave, ITV News revealed hospices were caring for 24,000 people a day – three times more than the same period in 2019. The government gave hospices £200 million to help get through the COVID-19 crises after ITV News found hospices had lost £70 million in the first month of the pandemic as fundraising all but stopped following the national lockdown. <https://bit.ly/33UBirT>

Noted in Media Watch 4 May 2020 (#664, p.2):

- U.K. | *Press Gazette* – 1 May 2020 – ‘**Best investigative journalism of the Coronavirus crises revealed.**’ News media investigations have helped shed light on the impact of the Coronavirus on the most vulnerable in society and, in doing so, pushed for action from officials. Among the investigations highlighted in a recent ‘Journalism Matters: Excellence in Reporting Coronavirus’ survey, undertaken by the trade magazine, is one by ITV, which shed light on the precarious funding of hospices in the U.K.¹ The vast majority of end-of-life care in the U.K. is paid for through fundraising, which stopped overnight more or less when the virus hit. ITV’s investigation eventually led to the government giving the sector £200 million to help them through the next three months. <https://bit.ly/2KQaj7G>

1. ‘Hospices issue dire warning of closures as Coronavirus sparks cutbacks in end-of life-care,’ ITV, 28 March 2020. <https://bit.ly/3aVPhPB>

National Institute for Health & Care Excellence Impact End-of-Life Care for Adults

U.K. (England) | National Institute for Health & Care Excellence – Accessed 21 September 2020 – Around half-a-million people die in England each year. With an ageing population, the annual number of deaths is projected to increase. In addition, the COVID-19 pandemic has led to an increase in the excess death rate. The ‘One Chance to Get it Right’ report from the Leadership Alliance for the Care of Dying People states that people are approaching the end of life when they are likely to die within the next 12 months.¹ This includes people whose death is imminent as well as those with conditions that mean they are expected to die within 12 months. End-of-life care (EoLC) enables supportive and palliative care (PC) needs to be identified and met throughout the last phase of life and into bereavement. It is achieved by early identification, assessment and treatment of pain and other distressing symp-

toms, while integrating the psychological, social and spiritual aspects of the person’s care. There is a lack of published data about EoLC services for the last 12 months of life, so the main focus of this report is on care in the last 2 to 3 days of life in acute settings. **Download/view report at:** <https://bit.ly/3iQyTVf>

Impact of COVID-19 on EoLC

This report looks at the impact of the Institute’s guidance using data collected before the COVID-19 pandemic. In response to COVID-19, care has been delivered differently. As a result, some people and those important to them may have had a less positive experience. The full impact the pandemic has had on EoLC is not known. It is likely that changes made during this time will influence how care is delivered in the future.

1. ‘One Chance to Get it Right: Improving people’s experience of care in the last few days and hours of life,’ Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch 30 June 2014 (#364, p.7)] **Download/view at:** <http://bit.ly/33Cx5HE>

Over 26% of terminal cancer patients ended life-sustaining treatment

SOUTH KOREA | KBS World Radio (Seoul) – 21 September 2020 – The National Evidence-Based Healthcare Collaborating Agency has disclosed data collected in the year since a new law on life-sustaining treatment went into effect in February 2018. Such treatment refers to medical procedures that simply prolong a patient's life without providing any curing effects such as CPR, artificial respirators, hemodialysis or anticancer medicine. The findings show 26% of over 54,600 adult cancer patients who died during the one-year period through January 2019 chose not to receive life-sustaining treatment from the beginning or suspended it. Among patients aged under 65, nearly 34% ended treatment compared to 23% among those 65 and older. Over 60% of terminal cancer patients in their 40s and 50s especially made the decision on their own without necessarily seeking consent from their families. <https://bit.ly/30532sF>

N.B. Additional articles on South Korea's 'Act on Decisions on Life-Sustaining Treatment for Patients in Hospice & Palliative Care or at the End of Life' noted in Media Watch 8 June 2020 (#669, p.9)

Specialist Publications

Dying patients with chronic obstructive pulmonary disease subjected to testing despite shift to comfort care, study finds

AMERICAN JOURNAL OF MANAGED CARE | Online – 23 September 2020 – There are missed opportunities for reducing diagnostic tests and focusing on comfort at the end of life (EoL) for patients with chronic obstructive pulmonary disease, according to researchers, whose study findings discovered a high burden of testing on patients dying with the disease in the hospital, even after a decision to provide comfort care only in some cases.¹ As a result, the researchers are calling for enhanced clinical training on EoL care and managing death and strategies to improve communication to address the issue. The researchers retrospectively examined the medical record audits of 343 patients from 2 Australian hospitals over a 12-year period and identified a median of 11 diagnostic testing episodes per patient. Nearly every patient received diagnostic

tests during their terminal admission. Notably, most patients (81%) received diagnostic testing in their last 2 days of life and 12% of patients underwent ongoing investigations even after the care team had determined the patient was actively dying and had refocused the goal of care to comfort. Slightly more than one-third had at least 1 test performed on the day of their death; of those 108 patients, 36 died on the same day they were admitted to hospital. <https://bit.ly/368DdeW>

Publishing Matters

'Mandatory disclosure of financial interests of journals and editors' (p.16), in *British Medical Journal*.

1. 'The burden of diagnostic investigations at the end of life for people with COPD,' *Internal Medicine Journal*, published online 16 June 2020. **Abstract:** <https://bit.ly/348LsW7>

Economic and clinical outcomes of the nurse practitioner-led Sydney Adventist Hospital Community Palliative Care Service

AUSTRALIAN HEALTH REVIEW | Online – 22 September 2020 – National trends [in Australia] show an emphasis on community services with the aim of promoting and supporting the choice of dying at home, and this coincides with drives to reduce hospital costs and length of stay. Community-based palliative care (PC) services may offer substantial economic and clinical benefits. The Sydney Adventist Hospital Community Palliative Care Service was the first nurse practitioner-led community-based PC service in Australia. The expansion of this service led to significantly fewer admissions and deaths in hospital, and halved the estimated hospitalisation cost per patient. **Abstract (w. list of references):** <https://bit.ly/3mHv4US>

Cont.

Related:

- *BMC MEDICINE* | Online – 22 September 2020 – ‘**Decreased costs and retained quality of life due to the ‘PACE Steps to Success’ intervention in long-term care facilities: Cost-effectiveness analysis of a randomized controlled trial.**’ Costs decreased and quality of life (QoL) was retained due to the ‘PACE Steps to Success’ intervention. Significant cost savings and improvement in quality of end of life of the intervention group was found. This indicates that timely palliative care (PC) in the long-term care (LTCF) setting can prevent lengthy hospitalizations while retaining QoL. Integrating general PC into daily routine in LTCFs can be cost-effective. **Full text:** <https://bit.ly/3cjJgyB>

What do you mean by “palliative sedation”?

BMC PALLIATIVE CARE | Online – 23 September 2020 – There is a lack of consensus and a high potential even for different kinds of confusion regarding the labeling of sedation practices in palliative care (PC). Separate solution strategies can be formulated for these different kinds of problems. Calling for uniformity of definitions alone, without an understanding of the underlying types of problems, will not help to improve the conceptual situation concerning sedation in PC. Instead, the categories presented and the authors’ analyses of impact on conceptual problems in different ways can serve as a starting point when constructing terminology. They can guide reflection on the intuitive use of terms and be used to explore whether concepts are confused in communication in research or everyday practice. In addition, the authors’ methodological distinction of different purposes of the definition and implications may further the dissent on pre-emption of the ethical dispute about sedation practices in PC. **Full text:** <https://bit.ly/2FVyfaW>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 September 2020 – ‘**Clinical aspects of palliative sedation in prospective studies. A systematic review.**’ Clinical guidelines have been developed, but they are mainly based on expert opinion or retrospective chart reviews. Therefore, evidence for the clinical aspects of palliative sedation is needed. Ten prospective articles were included... Most frequently reported refractory symptoms were delirium (41-83%), pain (25-65%), and dyspnoea (16-59%). In some articles, psychological and existential distress were mentioned (16-59%). A few articles specified the tools used to assess symptoms. Future research needs to evaluate the effectiveness of palliative sedation for refractory symptom relief. **Abstract (w. list of references):** <https://bit.ly/33QyUCC>

N.B. Additional articles on palliative (or terminal) sedation noted in Media Watch 20 July 2020 (#675, p.7).

Co-construction of the family-focused support conversation: A participatory learning and action research study to implement support for family members whose relatives are being discharged for end-of-life care at home or in a nursing home

BMC PALLIATIVE CARE | Online – 21 September 2020 – Many people move in and out of hospital in the last few weeks of life. These care transitions can be distressing for family members because they signify the deterioration and impending death of their ill relative and forthcoming family bereavement. Whilst there is evidence about psychosocial support for family members providing end-of-life care (EoLC) at home, there is limited evidence about how this can be provided in acute hospitals during care transitions. Consequently, family members report a lack of support from hospital-based healthcare professionals. Through a process of co-construction, the authors designed an evidence-based structured conversation, the Family-Focused Support Conversation. Pilot implementation demonstrated the intervention has the potential to be adopted in acute hospitals, and addresses family concerns about the meaning and significance of discharge, implications about EoLC needs and how family caregiving can be managed and enhanced. **Full text:** <https://bit.ly/2ZYIe5X>



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Supportive and palliative care in the age of deferred death: Primary care's central role

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 24 September 2020 – The structure of formal supportive and palliative care (PC) that has evolved – specialist PC – works best for people with cancer who only make up a fifth of those who die in old age. The trajectory of dying in progressive cancer is predictable and relatively short, so designing services for them is relatively straightforward. It is far more challenging to provide care for people with advanced diseases when the time frame is long and the course uncertain. The prevailing service model of specialist single-organ care can unintentionally create exhausting treatment burdens, potential for error and care duplication, especially in multimorbid patients. Non-physical dimensions can be, and often are, neglected in a disease systems-centred approach. Crucially, often no one coordinates care where multiple specialists are involved. The well-being of those who shoulder the greatest burden of care – close family – can often be entirely ignored. Critical evaluation of the entire health system and the philosophies that underpin it are required urgently as many people still die without any access to PC at all. **Introduction:** <https://bit.ly/3cvZDYQ>

Palliative care from the perspective of cancer physicians: A qualitative semi-structured interviews study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 September 2020 – Integrated palliative care (PC) for populations with cancer is now highly recommended. However, numerous physicians working in cancer care are still reluctant to refer patients to specialist PC teams. This study explores their perceptions of PC and factors influencing reasons to refer to specialist PC. Data analysis found four themes: 1) Symptom management as a trigger; 2) Psychosocial support; 3) Mediation provided by interventions; and, 4) The association with terminal care or death. PC integrated interventions were mainly perceived as holistic approaches that offered symptom management expertise and time. They were valued

for helping in consolidating decision-making from a different or external perspective, or an “outside look.” Several barriers were identified, often due to the confusion between terminal care and PC. This was further highlighted by the avoidance of the words “palliative care,” which were associated with death. **Abstract:** <https://bit.ly/33RPbqJ>

Extract from *BMJ Supportive & Palliative Care* article

National policies for promoting PC seemed to have failed in switching oncologists' perception of PC, which they still consider as terminal care.

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 21 September 2020 – ‘**Exploring the reasons cancer survivors do not seek help for their concerns: A descriptive content analysis.**’ 13,319 survey respondents answered the question about seeking help: 87% had a physical concern of which 76% did not seek help; 77% had an emotional concern of which 82% did not seek help; and, 45% had a practical concern of which 71% did not seek help. Reasons included being told it was normal and not thinking anything could be done, not wanting to ask, not thinking services were available, handling it on their own and not thinking it was serious enough to seek help. These findings can be useful to healthcare providers in proactively identifying/addressing needs of these survivors. **Abstract:** <https://bit.ly/3mIW5Hg>

A national survey of anaesthetists' preferences for their own end-of-life care

BRITISH JOURNAL OF ANAESTHESIA | Online – 17 September 2020 – This study provides the first systematic description of U.K. doctors', specifically anaesthetists', personal preferences for end-of-life care (EoLC). Broad trends were identified: to be well informed; to avoid high-intensity medical treatments if terminally unwell; to spend remaining time with family and friends; and, to be symptom-free and well cared for. However, a substantial minority expressed different, indeed opposite, opinions. This variation highlights that good quality EoLC must be driven by discussion of an individual's values, wishes, and preferences. **Abstract (w. list of references):** <https://bit.ly/3kER15d>

Cont.

Noted in Media Watch 29 July 2019 (#624, p.10):

- *MEDPAGE TODAY* | Online – 24 July 2019 – ‘**Docs no less likely than others to get aggressive end-of-life care.**’ Canadian physicians are just as likely as others in the general population to receive aggressive care as they neared death, researchers have found.¹ Among some 2,500 physicians who died in the province from April 2004 to March 2015, 52.9% made use of palliative care (PC) services in their last 6 months of life compared with 47.4% among about 7,500 non-doctors, along with lower odds of visiting an emergency department. Informed healthcare decision-makers such as physicians do not consistently opt for less-aggressive care across the board, but instead vary in their choices regarding end-of-life care, with increased use of both intensive and PC. **Full text:** <http://bit.ly/2Gv0rOT>

1. ‘End-of-life care received by physicians compared with non-physicians,’ *JAMA Open Network*, published online 24 July 2019. **Full text:** <http://bit.ly/2MdUuJV>

Noted in Media Watch 23 May 2016 (#463, p.12):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 16 May 2016 – ‘**How U.S. doctors die: A cohort study of healthcare use at the end of life.**’ Many believe that doctors in the U.S. die differently from the rest of society. The current findings suggest a more-mixed and nuanced picture. Doctors may be more likely to die using hospice, but they are no less likely to use high-intensity hospital care. If anything, they have higher rates of ICU use in the last 6 months of life. Society as a whole and policy-makers focused on containing healthcare costs in particular may be surprised to learn that even physicians, with knowledge of and experience with death and dying, have use of hospitals nearly identical to that of non-physicians. **Full text:** <http://bit.ly/30QI3aQ>

The difference an end-of-life diagnosis makes: Qualitative interviews with providers of community healthcare for frail older people

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 21 September 2020 – The findings of this study suggest that, as policymakers intend, an end-of-life (EoL) diagnosis benefits its recipient. However, they also highlight an unintended effect of policies centred on EoL diagnosis: such policies risk privileging people with a single life-limiting condition over people who die of a collection of age-related conditions. To mitigate this risk requires a rethink: is the “end-of-life” lens useful for thinking about how best to support frail older people and their families? More specifically, is it helpful to try to distinguish between a crisis that turns out to be at the EoL, and an identical crisis that turns out to be a temporary and reversible episode? Given the uncertainty of prognosis in this group of people, it is suggested that practitioners and policymakers should avoid increasing their focus on EoL diagnosis, and instead focus primarily on what each frail older individual needs. This shift would inform a more nuanced approach to clinicians’ conversations about care priorities, enabling them to situate such conversations within the web of practices through which they provide care to older people. For policymakers, commissioners, and managers, it would help to clarify the challenge of providing good EoL care equitably to all groups within their populations. **Full text:** <https://bit.ly/2HnBrfL>

Related:

- *BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 23 September 2020 – ‘**Physicians’ perspectives on estimating and communicating prognosis in palliative care: a cross-sectional survey.**’ The findings suggest that more shared professionalisation towards advance care planning (ACP) and communicating prognosis in palliative care may facilitate collaborative partnership in ACP between physicians working in different care settings. To achieve this, first, professional physicians’ associations should, in mutual consultation, give direction to the coordination of roles and responsibilities related to ACP. Second, education and training in practice require more attention for communicating poor prognosis and related preferences with patients and with other physicians. **Full text:** <https://bit.ly/3hWjKR3>

Breaking bad news to families in the COVID-19 pandemic: How do we adapt our practice?

BRITISH MEDICAL JOURNAL | Online – 20 September 2020 – The ability to communicate serious news to families compassionately is a core skill for all medical professionals. Within specialist palliative care we view ourselves as experts in this field and routinely break bad news in accordance with well-developed frameworks, while relying on our own professional experience and intuition. For the first time in our careers we are suddenly challenged with how to effectively deliver bad news to families in a humane manner. Due to the COVID-19 pandemic, it is no longer always possible to sit down in person with families to communicate challenging news. Visiting restrictions secondary to the COVID-19 pandemic have impacted healthcare services globally. With the need for ongoing widespread visiting restrictions, how can we adapt our approach to ensure we preserve core principles and break bad news to families in a compassionate manner on the phone or via video calls? The SPIKES for breaking bad news is the most commonly used and cited model in the literature. It is often used as the cornerstone for complex communication processes which involve discussing challenging issues with families. When faced with the need to communicate bad news to a family through a virtual format, is this framework helpful and how can we deliver best practice while acknowledging the limitations of such an approach? **Full text:** <https://bit.ly/3hVk1nb>

Noted in Media Watch 2 March 2020 (#655, p.13):

- *PATIENT EDUCATION & COUNSELING* | Online – 27 February 2020 – ‘**Assessing patients’ preferences for breaking bad news according to the SPIKES-Protocol: The MABBAN Scale.**’ The Marburg Breaking Bad News Scale was developed and administered to 336 cancer patients. The novel questionnaire supported the six SPIKES-components of breaking bad news: Setting, Perception, Invitation, Knowledge, Emotions, and Strategy. Depending on clinical and demographic variables different components were rated as important. Using SPIKES as a framework can optimize breaking bad news conversations but it seems important to emphasize the individual preferences beyond the six steps and tailor the communication process to the individual. **Abstract:** <http://bit.ly/2wgQmmh>

Identifying barriers and facilitators to implementing advance care planning in prisons: A rapid literature review

HEALTH & JUSTICE | Online – 21 September 2020 – Limited academic literature related to the implementation and experience of advance care planning (ACP) in prisons is available... Barriers and facilitators related to the implementation of ACP in prisons were grouped into systems-based factors, attitudes and perspectives of staff and prisoners, and understanding and knowledge of ACP by staff and prisoners. ACP and substitute decision-making appears poorly integrated into correctional health currently and barriers exist at the system, staff, and prisoner levels. As the number of older prisoners dying from natural causes is increasing, improving ACP uptake in prisons is essential to ensure prisoner medical treatment preferences are respected. Further research is needed to better understand the attitudes, perspectives and experience with ACP for prisoners, prison-based health practitioners, correctional officers, and health practitioners providing care to prisoners. The participation of prisoners in such studies demonstrates their willingness to engage in research and issues regarding ACP, ethical treatment and end-of-life care. **Full text:** <https://bit.ly/2RQbIUS>

Advance Care
Planning Australia

Noted in Media Watch 15 October 2018 (#585, p.12):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY*, 2018;66(12):2382-2388. “‘**We take care of patients, but we don’t advocate for them**’: **Advance care planning in prison or jail.**’ Participants in this study demonstrated low baseline advance care planning (ACP) knowledge; 85% reported familiarity with ACP, but only 42% provided accurate definitions. Fundamental misconceptions included the belief that providers provided ACP without soliciting inmate input. Multiple ACP barriers were identified, many of which are unique to prison and jail facilities, including provider uncertainty about the legal validity of ACP documents in prison or jail, inmate mistrust of the correctional healthcare system, inmates’ isolation from family and friends, and institutional policies that restrict use of ACP. **Abstract:** <http://bit.ly/2HnEsu0>

Cont.

Noted in Media Watch 2 July 2018 (#570, p.18):

- *JOURNAL OF CORRECTIONAL HEALTH CARE*, 2018;24(3):232-242. **'Preparing to die behind bars: The journey of male inmates with terminal health conditions.'** While research has expanded on end-of-life care in and out of prison settings, to date there has been little research conducted on how inmates experience dying behind bars. Through collecting data during observation of facilitated advance care planning sessions, this qualitative study revealed four main themes: 1) Losing a piece of everything; 2) Not sure what to feel; 3) Where will I die; and, 4) Finding purpose in the midst of purposelessness. These themes characterize the central issues discussed by inmates as they considered death behind bars. This study provides insight into how inmates view their dying process. **Abstract:** <http://bit.ly/2JqhKUJ>

Ensuring adequate palliative and hospice care during COVID-19 surges

JOURNAL OF AMERICAN MEDICAL ASSOCIATION | Online – 21 September 2020 – An ethical approach to pandemic surge planning requires recognizing and addressing threats of scarcity throughout the community, including for patients whose primary goals are symptom relief and comfort at the end of life. Failure to plan for adequate palliative and hospice care when a substantial increase in disease and death is expected is unconscionable, and it risks undermining patient-family trust, long-term emotional health, and the core values of society. This has been recognized at least since the 2012 report on Crisis Standards of Care from the Institute of Medicine, which declared that “provision of palliative care in the context of a disaster with scarce resources can be considered a moral imperative of a humane society.”¹ That call to action was largely ignored in the first wave of this pandemic, but it is more real now than ever during ongoing threats of overwhelming local and regional surges in demand for palliative and hospice care. **Full text:** <https://bit.ly/35XANzV>

1. 'Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response,' Committee on Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations, Institute of National Academies, 2012. **Download/view at:** <https://bit.ly/32SLDW8>

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 September 2020 – **'How COVID-19 changed advance care planning: Insights from the West Virginia Center for End-of-Life Care.'** Prompted by the pandemic and heightened concerns about widespread illness, patients seeking healthcare in West Virginia contacted the Center to ensure their wishes were recorded and available to treating healthcare providers in an emergency. Even as the crisis of the pandemic appears to be subsiding, clinicians have noted a new openness of patients to engage in advance care planning (ACP) to maintain control over their healthcare. The changes seen in West Virginia may represent a glimpse into what may be a greater receptivity to ACP in this country in the future. **Full text:** <https://bit.ly/3cjLcan>

Balancing patient and societal interests in decisions about potentially life-sustaining treatment

JOURNAL OF BIOETHICAL INQUIRY | Online – 22 September 2020 – The authors investigate the content of Australian policies that address withholding or withdrawing life-sustaining treatment to analyse the guidance they provide to doctors about the allocation of resources. All publicly available non-institutional policies on withholding and withdrawing life-sustaining treatment were identified, including codes of conduct and government and professional organization guidelines. The policies that referred to resource allocation were isolated and analysed... Eight Australian policies addressed both withholding and withdrawing life-sustaining treatment and resource allocation. Four resource-related themes were identified: 1) Doctors' ethical duties to consider resource allocation; 2) Balancing ethical obligations to patient and society; 3) Fair process and transparent resource allocation; and, 4) Legal guidance on distributive justice as a rationale to limit life-sustaining treatment. Of the policies that addressed resource allocation, this review found broad agreement about the existence of doctors' duties to consider the stewardship of scarce resources in decision-making. There was disparity in the guidance about how to reconcile competing duties to patient and society. There is a need to better address the difficult and confronting issue of the role of scarce resources in decisions about life-sustaining treatment. **Abstract (w. footnotes and list of references):** <https://bit.ly/340a43f>

Top ten tips palliative care clinicians should know about cognitive impairment

JOURNAL OF PALLIATIVE MEDICINE | Online – 21 September 2020 – Most long-term care (LTC) residents are of age >65 years and have multiple chronic health conditions affecting their cognitive and physical functioning. Although some individuals in nursing homes return home after receiving therapy services, most will remain in a LTC facility until their deaths. This article seeks to provide guidance on how to assess and effectively select treatment for delirium, behavioral and psychological symptoms for patients with dementia, and address other common challenges such as advanced care planning, decision-making capacity, and artificial hydration at the end of life. **Abstract:** <https://bit.ly/2FHrtFO>

Noted in Media Watch 29 June 2020 (#672, p.10):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 25 June 2020 – ‘**Associations between unmet palliative care needs and cognitive impairment in a sample of diverse, community-based older adults.**’ The Montreal Cognitive Assessment and the Unmet Palliative Care Needs screening tools were used in this study to assess participants’ cognitive status and palliative care (PC) needs. Findings revealed a quadratic relationship between unmet PC needs and mild cognitive impairment... This study is a first step toward elucidating the relationship between cognitive impairment and PC needs in a diverse community sample of older adults. More research is needed to better understand the unique PC needs of older adults with cognitive impairment living in the community. **Abstract (w. list of references):** <https://bit.ly/2BfBqaZ>

Home-based end-of-life care for children and their families: A systematic scoping review and narrative synthesis

JOURNAL OF PEDIATRIC NURSING, 2020;55(6):126-133. There is a growing international drive to deliver children’s palliative care (PC) services closer to home. This review aims to establish the current international evidence base relating to children’s EoLC at home. Twenty-three papers met the eligibility criteria and were included in the review. Engagement of families in EoLC planning discussions was identified as a key factor to facilitate choice of setting. Consistent themes from the data suggest that providing access to care in the home 24/7 by a team of professionals with specialist pediatric PC knowledge is an essential aspect of any model of home-based EoLC. This is the first comprehensive review of home-based EoLC for children which offers a valuable contribution to policy, practice and research. The evidence mapped and synthesised in this review can inform the development of services to facilitate the provision of EoLC at home in line with the unique wishes and needs of children and families. **Abstract (w. list of references):** <https://bit.ly/2HhoFQ2>

Noted in Media Watch 6 July 2020 (#673, p.6):

- *EUROPEAN JOURNAL OF PEDIATRICS* | Online – 30 June 2020 – ‘**Predictors for place of death among children: A systematic review and meta-analyses of recent literature.**’ Lower age was associated with higher odds of hospital death in eight studies... Children categorised as non-white were less likely to die at home compared to white ... as were children of low socio-economic position versus high... Compared to patients with cancer, children with non-cancer diagnoses had lower odds of home death... Country and region of residence, older age of the child, high socio-economic position, “white” ethnicity and cancer diagnoses appear to be independent predictors of home death among children. **Abstract (w. list of references):** <https://bit.ly/2NHYoKy>

Noted in Media Watch 30 December 2019 (#646, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 27 December 2019 – ‘**“There’s just no way to help, and they did”**: Parents name compassionate care as a new domain of quality in pediatric home-based hospice and palliative care.’ Although most of the provider-prioritized domains are pertinent to parents, parents [i.e., study participants] defined these domains differently, deepening understanding and perspective of quality within each domain. Parents also prioritize compassionate care as a new domain of quality in pediatric home-based hospice and palliative care (HBHPC). Measuring the quality of care provided in HBHPC programs through this broader perspective should enable the selection of measures which are truly patient- and family-centered. **Abstract:** <http://bit.ly/2t6eG9c>

Cont.

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2019 – ‘**Hospital or home? Where should children die and how do we make that a reality?**’ Most of the 20,000 U.S. children dying of serious illnesses annually die in the hospital. To better understand location of death preferences in North America, the authors reviewed the literature to examine the evidence for and against home death in seriously ill children. The authors’ findings should be interpreted with several caveats: 1) Many studies are small and prone to selection bias; 2) Not all families prefer home death and some that do are not able to achieve home death due to inadequate home support; and, 3) Studies of bereavement outcomes are lacking. **Abstract (w. list of references):** <http://bit.ly/350tcMJ>

Practice considerations for trauma-informed care at end of life

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 22 September 2020 – Trauma is widespread, and its symptoms can adversely impact wellbeing at end of life (EoL), a time when hospice seeks to maximize quality of life. This article reviews research on trauma at EoL, provides an overview of trauma-informed principles, and explores possibilities for applying trauma-informed care through an illustrative case study of a patient at EoL. As shown in the case study, trauma-related symptoms may complicate care, making it an important subject of clinical attention for interdisciplinary hospice team members. As part of this team, social workers are particularly well suited to provide more targeted interventions where indicated, though all members of the team should take a trauma-informed approach. Lastly, this article reflects on the need for organizations to take a systems-level approach when implementing trauma-informed care and suggests implications for practice through a universal approach to trauma and the need for trauma-specific assessments and interventions at EoL, along with areas for future research. **Abstract:** <https://bit.ly/3iVlprz>

National Children’s Hospitals Bereavement Network standards for supporting families following the death of a child

NURSING CHILDREN & YOUNG PEOPLE | Online – 23 September 2020 – In England, a child death review process must be undertaken when a child dies, regardless of the cause of death. Scotland and Wales have their own version of the child death review process, while it is the author’s understanding that Northern Ireland are still developing their process. An important aspect of this process is family engagement and bereavement support. This article is an introduction to the bereavement support standards developed by the National Children’s Hospitals Bereavement Network, a newly formed group of specialist children’s nurses and allied health professionals interested in bereavement care. These standards translate the statutory requirements into practical guidance for healthcare professionals working in children’s hospitals in the U.K. or district general hospitals that offer services for children and families. They also apply to National Health Service (NHS) trusts that care for children and need to develop a local policy and workforce with the

appropriate skills to provide bereavement care, thereby improving the experiences of families and healthcare professionals. The standards would also be applicable to other NHS trusts and healthcare services in the U.K. who want to develop an approach to bereavement care and support for families. **Abstract:** <https://bit.ly/2RX9jSR>



The Crossroads of Grief:
Understanding Grief & Diversity
<http://bit.ly/2OB4Y6C>



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

“My wife is my doctor at home”: A qualitative study exploring the challenges of home-based palliative care in a resource-poor setting

PALLIATIVE MEDICINE | Online – 18 September 2020 – Palliative care (PC) services are limited, and in the early stages of development in the study’s context. Given the geography and poor infrastructure, such as poor internet access, the answer does not lie in a straightforward application of Westernised PC models, but the authors argue that family caregivers (FCGs) need to be better supported. In the meantime, satellite PC services, the use of telemedicine, or the sharing of information on mobile apps could support patients and their FCGs to navigate care at home. For any potential online resources, this should take into account the poor internet access and literacy rate. There is a clear need for person-centered care that is coordinated by both professionals and FCGs. This could be supported by a comprehensive health and social care policy underpinned by significant resources to facilitate the development of home-based care delivered by healthcare professionals in the long term. Training of healthcare professionals to provide appropriate support for this population while relying on the existing family support networks is required. The authors call for the building of compassionate communities and home-based networks for the care of the dying, such as those being advocated in public health approaches to PC that is tailored to the context. **Full text:** <https://bit.ly/35Vv8ug>

Intensity of predeath grief and post-death grief of family caregivers in palliative care in relation to preparedness for caregiving, caregiver burden, and social support

PALLIATIVE MEDICINE REPORTS | Online – 15 September 2020 – The results of this prospective correlational study in a palliative care context add to knowledge about the complexity and significance of caregiver burden and social support in relation to the grief process of family caregivers (FCGs). The results demonstrate that a high caregiver burden is associated with higher pre-death grief. Furthermore, results show that the association between intensity of pre-death grief and post-death grief in FCGs could be moderated, especially by low caregiver burden and low social support. Hence, the results emphasize that special attention should be directed to these variables, bearing in mind that, together with high pre-death grief, low caregiver burden may also imply a need for support in bereavement. Acknowledging pre-death grief during caregiving and recognizing predeath grief and post-death grief as parts of the same process are of importance, both in everyday clinical practice and when designing supportive interventions. FCGs may benefit from conversations with healthcare professionals, including opportunities to talk about their individual resources and needs. Further research is needed to enhance the understanding of the interplay between different variables in the grief process. **Full text:** <https://bit.ly/3cjdIZI>

Palliative care in public policy: Results from a global survey

PALLIATIVE MEDICINE REPORTS | Online – 15 September 2020 – National policy recognition for palliative care (PC) is far from universal and is generally (though not exclusively) confined to high-income countries. There is some evidence, however, that a significant number of others, including low- and middle-income countries, are making progress in this direction. A 2015 World Health Organization (WHO) survey reported that 37% of countries had an operational national policy for noncommunicable diseases that included PC.¹ This is a higher figure than the authors report for the number of countries with a stand-alone policy. Two factors may explain the difference. First the WHO study looked for the inclusion of PC within a wider policy commitment, whereas the survey focused on stand-alone plans or strategies for PC. Second, the WHO study drew on reports from government officials (who perhaps might be inclined to inflate levels of attention to PC), whereas the authors’ main sources were PC activists and experts (perhaps inclined to underestimate or downplay the presence of such policies). The authors recognize that methodological issues of this kind are still to be fully overcome if we are to generate more accurate information on many aspects of global PC development. There are also wider more conceptual challenges. The creation and implementation of PC policy face specific psychological, political, financial, and social barriers. **Full text:** <https://bit.ly/2G44pAw>

1. ‘National palliative care capacities around the world: Results from the World Health Organization Non-communicable Disease Country Capacity Survey,’ *Palliative Medicine*, published online 5 July 2017. [Noted in Media Watch 10 July 2017 (#520, p.15)]. **Abstract (w. list of references):** <https://bit.ly/3cnVbv3>

Rethinking palliative care in a public health context: Addressing the needs of persons with non-communicable chronic diseases

PRIMARY HEALTH CARE RESEARCH & DEVELOPMENT | Online

– 15 September 2020 – The European Innovation Partnership on Active & Healthy Aging working group focuses on well-being for older adults, with an emphasis on quality of life (QoL) and healthy aging.



European Innovation
Partnership on Active
and Healthy Ageing

A subgroup, including multidisciplinary stakeholders in healthcare across Europe, focuses on the palliative care (PC) model as a paradigm to be modified to meet the needs of older persons with non-communicable chronic diseases (NCCDs). This development paper delineates the key parameters identified as critical in creating a public health model of PC directed to the needs of persons with NCCDs. This paradigm shift should affect horizontal components of public health models. Furthermore, the model includes vertical components often neglected, such as nutrition, resilience, well-being and leisure activities. The main enablers identified are information and communication technologies, education and training programs, communities of compassion, twinning activities, promoting research and increasing awareness amongst policymakers. Identified are key “bottlenecks”: inequity of access, insufficient research, inadequate development of advance care planning and a lack of co-creation of relevant technologies and shared decision-making. Rethinking PC within a public health context must focus on developing policies, training and technologies to enhance person-centered QoL for those with NCCD, while ensuring that they and those important to them experience death with dignity. **Abstract (w. list of references):** <https://bit.ly/2FNE9dL>

Noted in Media Watch 20 July 2020 (#675, p.11):

- *EUROPEAN JOURNAL OF CANCER*, 2020;136(9):95-98. ‘**COVID-19, palliative care and public health.**’ The lack of integration between public health approaches, cancer care and palliative and end-of-life care in the majority of health systems globally became strikingly evident in the context of the COVID-19 pandemic. At the same time, the collapse of the boundaries between these domains imposed by the pandemic created unique opportunities for intersectoral planning and collaboration. While the challenge of integration is not unique to oncology, the organisation of cancer care and its linkages to palliative care and to global health may allow it to be a demonstration model for how the problem of integration can be addressed. **Abstract (w. list of references):** <https://bit.ly/2OhJTG>

Noted in Media Watch 9 December 2019 (#643, p.7):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 4 December 2019 – ‘**A public health approach to palliative care in the Canadian context.** Many groups, including the World Health Organization, have advocated for a public health approach to palliative care (PC) as an antidote to fragmented service delivery. Multiple scholars, academics, and public health advocates have suggested that a public health approach to PC can help with issues of access, equity, and cost. This commentary explores potential reasons why a public health approach to PC has not been adopted in the Canadian context and why this is an opportune time to consider this policy innovation. **Abstract (w. list of references):** <http://bit.ly/2Lm5cwJ>

Noted in Media Match 25 February 2019 (#603, p.12):

- *PALLIATIVE CARE: RESEARCH & TREATMENT* | Online – 20 February 2019 – ‘**Palliative care and public health: An asymmetrical relationship?**’ The authors develop a range of critical perspectives on the relationship between public health (PH) and palliative care by scrutinising its claims of utility and effectiveness and questioning the strength of the interdisciplinary interaction between the two disciplines. They see their relationship in a “cross disciplinary” context which is still largely symbolic and tactical in nature. The authors considers the significance of these insights for policy and practice, with two possible scenarios. If the use of PH is essentially figurative and its resources are not unique, the particular and exclusive use of the term becomes insignificant. **Full text:** <http://bit.ly/2Xhk1oG>

Cont.

Noted in Media Watch 4 February 2019 (#600, p.9):

- *HEALTH PROMOTION INTERNATIONAL*, 2020;35(1):160-170. ‘**Unpacking “the cloud”**: A framework for implementing public health approaches to palliative care.’ The Health Impact Change Model (HICM) was developed to unpack the complexities associated with the implementation and evaluation of a Canadian compassionate communities intervention. The HICM offers utility for citizens, leaders and decision-makers who are engaged in the implementation of population health level strategies or other social approaches to care, such as compassionate cities and age or dementia-friendly communities. The HICM’s concepts can be adapted to address a community’s healthcare context, needs, and goals for change. **Abstract:** <http://bit.ly/2RrPggd>

Palliative care for asylum seekers living in the community in Australia

PROGRESS IN PALLIATIVE CARE | Online – 23 September 2020 – Australia is one of the most successful multi-cultural countries in the world, resulting from continuous immigration for the last 70 years or so. Australia is home for people from almost 200 countries with more than one in five speaking a language other than English at home. Some people arrive in Australia seeking protection from conflict in their own country. They may seek protection as a refugee and in the meantime live in the community while awaiting the outcome of their asylum request. Drawing on a story of one asylum seeker, the authors describe some of the key considerations required in caring for an asylum seeker who is facing the end of their life, making recommendations for addressing their often-complex care needs. **Abstract:** <https://bit.ly/33LYGYk>

Palliative space-time: Expanding and contracting geographies of U.S. healthcare

SOCIAL SCIENCE & MEDICINE | Online – 19 September 2020 – Two important changes are happening in healthcare in the U.S. As hospitals close in high numbers, the geographies of healthcare services are changing. Also, the ageing of the population brings about new and complex care needs. These are not discrete trends, as ageing impacts the who, what, and where of care needs, and hospital closures remakes the geographies of where people overall access care. Developed out of research on the impacts of hospital restructuring on workers, patients, and communities, this article aims to understand how healthcare financing, care needs for the ageing, and new geographies of health services are intertwined. To do so, the author looked back to 1980s policy changes to Medicare, the federal health insurance program for the elderly and disabled. In 1982, Congress made two important changes to Medicare. The program began covering hospice services, constituting an expansion of care, and the government drastically changed the way it reimburses providers, effectively a contraction of the program. The author traces the impacts of these changes over the next decades through analysis of media coverage and secondary research on hospital budgets. Drawing on the concept of palliative space-time, she identifies a contradictory logic of death at the center of this expansion and contraction of the healthcare system. This death logic works to destabilize an already uneven geography of health service. Yet, this crisis has the potential for more just geographies of health and care. **Full text:** <https://bit.ly/2RZaCAR>



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>

Publishing Matters

Mandatory disclosure of financial interests of journals and editors

BRITISH MEDICAL JOURNAL | Online – 23 September 2020 – Transparency of interests (or potential conflicting interests) by editors and authors allows readers to judge whether these are relevant for the interpretation of the article. Authors who fail to disclose conflicts of interest (COIs) may face consequences. For example, as of April 2020 conflict of interest was listed in the reasons for retraction for 165 articles in the Retraction Watch database and was the sole reason for the retraction of 19 (11%) articles. Failure to disclose COIs has led to job loss in some cases, and the International Committee of Medical Journal Editors considers non-disclosure as research misconduct. Journal editors, however, do not face such recriminations because readers do not know about their potential COIs as they are rarely available in the public domain. This lack of transparency jeopardises journals and professional organisations credibility and trust, especially as the publication business is highly profitable. We believe that journal editors, their professional organisations, and commercial publishers should not only have policies for the public disclosure of potential COIs of editorial team members but fully implement them. To be fully transparent, journals should also disclose their financial interests each year. **Introductory paragraphs:** <https://bit.ly/3iXLN3R>

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