

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.

20 July 2020 Edition | Issue #675



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The phrase upside down may point towards dynamic solutions to arm the palliative care community to better tackle this crisis.

'Upside down solutions: Palliative care and COVID-19' (p.11), in *BMJ Supportive & Palliative Care*.

Canada

Palliative care has been lacking for decades in long-term care

POLICY OPTIONS | Online – 16 July 2020 – As Canada discusses reforming nursing homes in the wake of **COVID-19**, it is important that we recognize the need for early, integrated palliative care (PC). What this means is that suffering is monitored and then addressed in a timely fashion when required, not just in the last days or weeks. It means that we attend to the physical and emotional well-being of patients and their families while continuing to learn about what quality of life means for them. This care happens while patients are being treated for their underlying illnesses and continues after they or their doctors decide that treatment is no longer helpful, desirable or necessary. PC does not hasten death, as some people believe. It improves the quality of life that remains. And it should not be reserved for the last desperate hours or days, because suffering usually starts much earlier. Importantly, it can be provided

alongside other treatments to sustain life, if appropriate. PC is built on frequent, deep conversations between health workers, patients and their family members. The goals of these conversations are to ensure that patients and families understand the medical situation and the healthcare team understands what is important to the patient in the time that is left. These essential discussions take time and trained health workers – something in short supply in the nursing home system. <https://bit.ly/2B5GAXb>

Specialist Publications

'What variables contribute to the achievement of a preferred home death for cancer patients in receipt of home-based palliative care in Canada?' (p.9), in *Cancer Nursing*.

Cont. next page



Would this article be of interest to a colleague?

Noted in Media Watch 22 June 2020 (#671, p.1):

- *HEALTHY DEBATE* | Online – 16 June 2020 – ‘**Not scared of dying but of dying scared.**’ COVID-19 has shone a bright light on a flawed system in need of dramatic reform, and on a workforce that must be better supported and empowered to provide meaningful end-of-life (EoL) care. This is not to place blame at the feet of our underpaid and undervalued care workers. These workers are cycling in and out of and in-between long-term care (LTC) settings without proper resources, training and educational supports. This workforce, much like the residents that they care for in an ageist society, has been largely ignored. While COVID-19 has brought this issue into focus, the lack of EoL support in LTC has been an ongoing injustice. <https://bit.ly/37F4bJS>

The pandemic has disrupted death and mourning in ways we don’t yet understand

MACLEAN’S MAGAZINE | Online – 15 July 2020 – The act of being present for a dying loved one can be an initial processing of grief, but often family members of coronavirus patients aren’t allowed visits until the very end. COVID-19 may be setting the stage for a “tsunami of grief.” The virus, which has killed 8,639 Canadians as of 1 July, has disrupted dying and grieving for all these families, regardless of the cause of death. “This is not a good time to die,” says Dr. Harvey Chochinov, a psychiatrist and director of the Manitoba Palliative Care Research Unit in Winnipeg. Chochinov estimates that, since the pandemic was declared in March, 60,000 to 70,000 Canadians have died from causes other than COVID-19. Each of those deaths has, in some way, been tainted by the pandemic, which has limited visits in hospitals and long-term care homes, and led to restrictions on public memorial services, as well as high levels of stress across the population. Even the most elemental offering of comfort to another human being – touch – is off limits to all but the innermost circle. Grief, in and of itself, is an isolating experience; grief in the context of a pandemic that necessitates physical distancing and is raising death rates may be unprecedented in scale, complexity and loneliness. For every death, about five people are profoundly affected, says Chochinov. By that estimate, about a million and a half Canadians in the first year of this pandemic will be forced to deal with a kind of grief “the likes of which we’ve never seen, and can’t pretend or claim to understand.” He predicts that we “are facing a tsunami of grief ahead.” <https://bit.ly/2OyuAAB>

Australia offers lesson in palliative care

HEALTHY DEBATE | Online – 15 July 2020 – In May, Palliative Care Australia ... released a report highlighting the need to overhaul the palliative care (PC) system in Australia while also making significant investments in the system to realize cost savings.¹ According to the ... report: “All Australians who need PC are simply not having access to services when they need to, particularly at home and in community settings. As we prepare for an ageing population and other unexpected stresses to our healthcare system, like COVID-19, we must look seriously at reforming our system to ensure it can meet people’s needs into the future. PC is about quality of life, living well with a palliative diagnosis and about dying well. Through an additional annual investment of \$365 million on national reform, we can save up to \$464 million in other health system costs while making the system work best for those experiencing it. We have to spend money to save money and that’s backed by leading economists.” Why should this matter to Canadians? Because a similar approach is needed here. The Institute for Clinical Evaluative Sciences (ICES) has reported that community-based PC reduces emergency room use and hospitalizations, decreases aggressive medical interventions and provides better quality care when compared to usual care.² In some cases, patients live longer when they receive high-quality PC. A Canadian Society for Palliative Care Physicians report shows that inpatient PC services can save \$7,000-\$8,000 per hospitalization and reduce hospital costs by 24%.³ A recent ... study highlights the potential benefits of PC in non-cancer illnesses.⁴ PC was associated with 12% reductions in emergency department visits and hospital admissions and a 41% reduction in intensive care unit admissions from patients dying from chronic organ failure (such as heart failure, cirrhosis, and stroke). <https://bit.ly/2WlQo6y>

1. ‘Investing to Save – The economics of increased investment in palliative care in Australia,’ Palliative Care Australia, May 2020. [Noted in Media Watch 1 June 2020 (#668, p.5)] **Download/view at:** <https://bit.ly/3d8DFL2>

Cont.

2. 'Palliative care delivery across health sectors: A population-level observational study,' *Palliative Medicine*, published online 16 June 2016. [Noted in Media Watch 20 June 2016 (#467, p.15)] **Full text:** <http://bit.ly/31NjzQ8>
3. 'How to improve palliative care in Canada: A call to action for federal, provincial, territorial, regional and local decision-makers,' Canadian Society of Palliative Care Physicians, November 2016. [Noted in Media Watch 7 November 2016 (#486, p.2)] **Download/view at:** <http://bit.ly/2NjQvKy>
4. 'Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: Population based matched cohort study,' *British Medical Journal*, published online 6 July 2020. [Noted in Media Watch 13 July 2020 (#674, p.8). **Full text:** <https://bit.ly/2O2Ds0Q>

N.B. See 'A (lack-of) action plan for palliative care in Canada,' Canadian Healthcare Network, posted online 23 October 2019. [Noted in Media Watch 4 November 2019 (#638, p.1)] <http://bit.ly/2Pp0JMs>

U.S.A.

An invisible hand: Patients aren't being told about the AI systems advising their care

STAT | Online – 15 July 2020 – At a growing number of prominent hospitals and clinics around the country, clinicians are turning to AI-powered decision support tools – many of them unproven – to help predict whether hospitalized patients are likely to develop complications or deteriorate, whether they're at risk of readmission, and whether they're likely to die soon. But these patients and their family members are often not informed about or asked to consent to the use of these tools in their care, a *STAT* examination has found. The result: Machines that are completely invisible to patients are increasingly guiding decision-making in the clinic. Hospitals and clinicians "are operating under the assumption that you do not disclose, and that's not really something that has been defended or really thought about," Harvard Law School professor Glenn Cohen said. Cohen is the author of

one of only a few authors examining the issue, which has received surprisingly scant attention in the medical literature even as research about artificial intelligence and machine learning proliferates. <https://bit.ly/3ezygwq>

Extract from *STAT* article

"I think that patients will find out that we are using these approaches, in part because people are writing news stories like this one about the fact that people are using them," said Justin Sanders, a palliative care physician at Dana-Farber Cancer Institute and Brigham & Women's Hospital in Boston. "It has the potential to become an unnecessary distraction and undermine trust in what we're trying to do in ways that are probably avoidable."

1. 'Informed consent and medical artificial intelligence: What to tell the patient?' *Georgetown Law Journal*, published online 22 June 2020. **Full text (click on pdf icon):** <https://bit.ly/2CcCVHy>

Noted in Media Watch 6 July 2020 (#673, p.2):

- *STAT* | Online – 1 July 2020 – '**An experiment in end-of-life care: Tapping AI's cold calculus to nudge the most human of conversations.**' The daily email that arrived in physician Samantha Wang's inbox ... contained a list of names and a warning: These patients are at high risk of dying within the next year. This list of names was generated by an algorithm that had reached its conclusions by scanning the patients' medical records. The email was meant as a nudge, to encourage Wang to broach a delicate conversation with her patient about his goals, values, and wishes for his care should his condition worsen. A handful of hospitals and clinics around the country are deploying cutting-edge artificial intelligence models in palliative care. <https://bit.ly/38g2Auu>

Cont.

Noted in Media Watch 2 March 2020 (#655, p.11):

- *THE LANCET*, 2020;395(10225):680-681. **'Power and perils of prediction in palliative care.'** Machine learning technologies can be useful in palliative care (PC), especially as clinicians and health systems seek to allocate and improve access to scarce PC resources. The potential of machine learning models in PC is their capacity to rapidly analyse data from various sources to predict who is likely to progress to unacceptable functional dependence or even die. Such predictions can signal who might need additional support, such as targeted communication or a PC consult. Appropriately timed introduction of PC services improves outcomes ... and healthcare spending efficiency. Figuring out who should get specialty PC and when is one of the field's most pressing questions. **Full text:** <http://bit.ly/2lqcUGV>

Hospices help address social isolation in patients

HOSPICE NEWS | Online – 13 July 2020 – The need for social distancing during the Coronavirus pandemic has exacerbated the adverse impacts of isolation on hospice patients' quality of life. Protecting the seriously ill at highest risk of COVID-19's impacts has come at the cost of human touch and hands-on care so integral to hospice patients in their final life stages. Hospice and palliative care (PC) providers have turned an increased focus on addressing isolation issues and connecting with patients from afar. Research has indicated significant links between the impacts of social isolation and increased risk of early mortality among older and seriously ill patients.¹ Not only is a patient's mental health impacted with greater risk of depression, anxiety and loneliness, but isolation also poses increased physical risks for those in the home without strong family and caregiver support and raises potential for hospitalizations and emergency room visits. The pandemic has further complicated issues of social isolation with the need to protect hospice and PC patients from exposure to COVID-19, as well as keep those who have been exposed or contracted the virus quarantined to prevent its spread. <https://bit.ly/2We4U0g>

1. 'Loneliness and social isolation as risk factors for mortality: A meta-analytic review,' *Perspectives on Psychological Science*, 2015;10(2):227-237. **Abstract:** <https://bit.ly/3i1xIDa>

Noted in Media Watch 9 March 2020 (#656, p.3):

- *MCKNIGHT'S LONG TERM CARE NEWS* | Online – 4 March 2020 – **'More screening for loneliness needed in vulnerable end-of-life stage, clinical experts stress.'** Clinicians must do more to screen for and intervene in cases of loneliness among older adults at the end-of-life (EoL) – not only during the dying period, say investigators from the University of Michigan.¹ Lonely older adults are burdened by more health symptoms and receive more intensive EoL care than their peers who don't suffer from loneliness... Loneliness is a pervasive psychosocial phenomenon with profound implications for the health and wellbeing of older adults throughout the life continuum, and particularly at the EoL. One-third of the nearly 2,900 older Americans studied reported loneliness... <http://bit.ly/2VLGprV>

1. 'The relationship of loneliness to end-of-life experience in older Americans: A cohort study,' *Journal of the American Geriatrics Society*, published online 3 March 2020. **Abstract:** <http://bit.ly/2libQ55>

Noted in Media Watch 18 February 2019 (#602, p.11):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 14 February 2019 – **'A practical approach to assessing and mitigating loneliness and isolation in older adults.'** There has been no uniform way of evaluating and documenting loneliness and social isolation as a part of a review of a patient's social determinants of health. This article provides a framework for healthcare systems, providers, and community members working with older adults to 1) Understand loneliness, isolation, and its counterpart social connection; 2) Describe the different ways loneliness affects health; and, 3) Create a framework for asking about and documenting these experiences. The authors provide guidance on the future of interventions. **Abstract:** <http://bit.ly/2S4KwJX>



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Palliative care consultations in heart failure associated with higher rates of advance care planning

MAINE | *Journal of Maine Medical Center*, 2020;2(2):Art.15. This study highlights a benefit to palliative medicine (PM) consultation for patients hospitalized with acute heart failure (HF). The rate of PM consultation was low for the patient population studied, although the authors observed slightly higher use than reported in previous studies. Without PM consultation, advanced care planning (ACP) was carried out less often than recommended in guidelines for HF patients. The authors also found that completion of ACP was higher for patients who received palliative medicine consultation. This result is consistent with previous findings that palliative medicine consultation in HF was associated with improved attitudes toward completing advance directives. Although palliative care has improved quality of life for HF patients, the authors did not assess this outcome... **Full text (click on pdf icon):** <https://bit.ly/2OdWBNT>

Noted in Media Watch 16 March 2020 (#657, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 March 2020 – ‘**Advance care planning in chronically ill persons diagnosed with heart failure or chronic obstructive pulmonary disease: An integrative review.**’ Chronic diseases such as heart failure and chronic obstructive pulmonary disease have a high symptom burden punctuated by exacerbations, making it difficult to know when introduction of advance care planning (ACP) discussions would be most beneficial. Future research should focus on a deeper evaluation of when to introduce ACP conversations in this population and which ACP interventions are effective to facilitate these discussions. **Abstract (w. list of references):** <http://bit.ly/2QbZuQh>

International

Caring for the terminally ill in prison

AUSTRALIA (Victoria) | *Pursuit* (University of Melbourne) – 14 July 2020 – With an increasing and, ageing population, there are now more people who are likely to face their end of life (EoL) in prison. Of those prisoners who die in Victoria, approximately 38% will spend their final weeks or months of life in a secure, guarded public hospital ward. The authors’ research uncovered the opportunities perceived by health professionals to improve the models of care for prisoners dying with progressive and life-limiting illnesses.¹ They explored the perspectives of public hospital-employed doctors, nurses and allied health staff from a range of disciplines about their experiences of providing care for dying prisoners in the public hospital setting. Health professionals described the unique constraints and obstacles faced by people in prison across a range of areas of care, and for themselves, as they strove to provide optimal EoL care for prisoners. They described the challenges in providing access to the best pain relief and facilitating death in a desired site of care. They also described a system which at times requires prisoners to forgo their minimum security incarceration and be transferred to a maximum secu-

urity facility in order to access specialist hospital care. Health professionals also identified the opportunities for improved clarity of protocols around some of the processes for dying prisoners – such as allowances to remove shackles when providing care, as well as considerations for healthcare professionals in advocating for compassionate release. <https://bit.ly/3eqeVh9>

Specialist Publications

‘Bereavement support in the U.K. – a rapid evidence assessment’ (p.7), in *Bereavement Care*.

‘Will they let me die? Perspectives of older Swiss adults on end-of-life issues’ (p.10), in *Death Studies*.

‘COVID-19, palliative care and public health’ (p.11), in *European Journal of Cancer*.

‘COVID-19: Guidance on palliative care from a European Respiratory Society international task force’ (p.12), in *European Respiratory Journal*.

Cont.

1. 'Complexities and constraints in end-of-life care for hospitalised prisoner patients,' *Journal of Pain & Symptom Management*, published online 24 May 2020. [Noted in Media Watch 1 June 2020 (#668, p.15)] **Abstract (w. link to references):** <https://bit.ly/2ZBnOk3>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 15 June 2020) can be downloaded/viewed from the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Specialist Publications

Polypharmacy, medication possession, and deprescribing of potentially non-beneficial drugs in hospice patients

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 July 2020 – Patients frequently have comorbidities that when combined with their primary diagnosis qualifies the patient for hospice. Consequently, patients are at risk for polypharmacy due to the number of medications prescribed to treat both the underlying conditions and the related symptoms. Polypharmacy is associated with negative consequences, including increased risk for adverse drug events, drug-drug and drug-disease interactions, reduced functional status and falls, multiple geriatric syndromes, medication non-adherence, and increased mortality. Polypharmacy also increases the complexity of medication management for caregivers and contributes to the cost of prescription drugs for hospices and patients. Deprescribing or removing non-

beneficial or ineffective medications can reduce polypharmacy in hospice. The authors studied medication possession ratios and rates of deprescribing of commonly prescribed but potentially non-beneficial classes of medication using a large hospice pharmacy database. Prevalence of some classes of potentially inappropriate medications is high. **Abstract (w. list of references):** <https://bit.ly/3gW3e3s>

Publishing Matters

'Is intentional publishing in predatory journals a form of scientific misconduct?' (p.15), in *South African Journal of Bioethics & Law*.

Noted in Media Watch 9 March 2020 (#656, p.9)

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 4 March 2020 – **'Improving drug therapy for patients with life-limiting illnesses: Let's take care of some low hanging fruit.'** A variety of strategies might address the current situation. At the facility or office level, quality improvement initiatives can include protocols to identify, re-evaluate, and deprescribe these drugs in patients with life-limiting illness. Hospitals, health systems, and nursing home chains can provide leadership, oversight, and support for focused quality improvement initiatives, and leverage the efficient use of electronic health records to identify and send reminders to prescribers about the lack of evidence for the use of these drugs in patients with life-limiting illness. **Full text:** <http://bit.ly/2wzMxZy>

Noted in Media Watch 6 January 2020 (#647, p.10):

- *SUPPORTIVE CARE IN CANCER* | Online – 23 December 2019 – **'The impact of palliative care consults on deprescribing in palliative cancer patients.'** Deprescribing in palliative cancer patients can benefit patients by reducing their pill burden, decrease potential side effects, and potentially decrease healthcare costs. A change in patients' goals-of-care (GoC) necessitates the alteration of drug therapy which includes both deprescribing and the addition of medications intended to improve quality of life. Depending on a patient's GoC, a medication can be considered as inappropriate. This study shows the positive impact a palliative consult has on deprescribing and reveals the importance of using guidelines for deprescribing in palliative cancer patients. **Abstract (w. list of references):** <http://bit.ly/2F1yU6L>

Specialist palliative care activity at an acute care tertiary hospital and its representation in administrative data

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 July 2020 – Palliative care (PC) specialists provide expert input into patient management, benefitting patients and other clinicians. Administrative data inadequately captures their involvement in patient care, especially consultations, and are therefore inappropriate for reporting specialist PC activity. Exclusion of information related to specialist PC activity results in an incomplete and distorted representation of PC services and fails to acknowledge the valuable contribution made by specialist PC. **Abstract:** <https://bit.ly/3h1YDwP>

Bereavement support in the U.K. – a rapid evidence assessment

BEREAVEMENT CARE, 2020;39(2):69-78. The main finding of the review was that the provision of bereavement support is extremely varied and there is no conclusive evidence for its effectiveness. There is widespread recognition of the potentially negative impact of bereavement on people, and a plethora of recommendations focused on raising awareness and ameliorating these effects have been made. However, the evidence for how best to support people experiencing bereavement is limited and contested. **Abstract (w. link to references):** <https://bit.ly/2ZDiMDj>

Continuous deep sedation and the doctrine of double effect: Do physicians not intend to make the patient unconscious until death if they gradually increase the sedatives?

BIOETHICS | Online – 14 July 2020 – Continuous deep sedation (CDS) has the effect of making the patient unconscious until death, and that it has this effect is clearly an undesirable aspect of CDS. However, some authors have recently maintained that many physicians do not intend this effect when practicing CDS. According to these authors, CDS is differentiated into two types; in what is called “gradual” CDS (or CDS as a result of proportionate palliative sedation), physicians start with low doses of sedatives and increase them only gradually, whereas in “rapid” CDS (or palliative sedation to unconsciousness), physicians rapidly administer a heavy dose that clearly induces unconsciousness from the beginning. The claim is that the physicians intend permanent unconsciousness only if they rapidly administer a heavy dose, but they do not intend it when the unconsciousness is the result of a gradual increase of sedatives. The author attempts to refute these claims based on a close examination of the protocol of gradual CDS. If his argument is valid, the doctrine of double effect would not be useful in justifying most, if not all, cases of CDS. **Full text:** <https://bit.ly/3ewSE1g>

Noted in Media Watch 9 March 2020 (#656, p.13):

- *NEW ENGLAND JOURNAL OF MEDICINE*, 2020;382(10):890-891. ‘**What are two days worth? Facing dilemmas together at the end of life.**’ Although the goal of palliative sedation is always control of refractory symptoms, we should all take pause when recommending it. In one national survey, most palliative care (PC) providers said they believed that its use was ethically appropriate, but a substantial proportion reported feeling distressed when recommending it to patients. It should be a treatment of last resort for a patient whose suffering cannot be relieved by any other means. For many specialist-level PC providers, it is a procedure done only in extreme circumstances, and many clinicians don’t endorse its use at all for existential suffering. **Access article at:** <http://bit.ly/2POQSPu>

N.B. Additional articles on palliative (or terminal) sedation noted in 2 March 2020 issue of Media Watch (#655, p.9).



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

Communication of advance care planning decisions: A retrospective cohort study of documents in general practice

BMC PALLIATIVE CARE | Online – 14 July 2020 – This study highlights the challenges faced by policy-makers charged with integrating paper-based legal documents into an electronic health record system. Internationally, health services are shifting away from paper-based communication and there is evidence that electronic health record systems improve the quality of patient care. However, much of the research on the impact of such records on the cost and efficiency of healthcare has been based within siloed record systems that are limited by a defined set of providers or settings. The greater challenge is how health information is communicated across electronic systems. Advanced care planning (ACP) documents are not only created and stored in different electronic records, but also in legal settings or held by consumers themselves. Such challenges are not exclusive to the Australian setting so this study also provides a foundation for future work in identifying methods and barriers to the communication of ACP documents both within and between healthcare providers. **Full text:** <https://bit.ly/3ewAlJs>

Related:

- *NURSING OLDER PEOPLE* | Online – 15 July 2020 – ‘**Advance care planning and decision-making in dementia care: A literature review.**’ This article reports on a literature review that aimed to explore the evidence on the introduction of advance care planning (ACP) in achieving preferred place of care or death for people living with dementia, and reducing carer burden. The review found that ACP discussions have several benefits for people with dementia and their family carers, but that various factors can support or hinder such discussions. It concludes that these people and their families need to plan for end of life and suggests that ACP can increase the likelihood of achieving their preferred place of care and death and reducing decisional burden for carers. **Abstract:** <https://bit.ly/2CdXTFZ>

A pilot evaluation of the Strengthening a Palliative Approach in Long-Term Care (SPA-LTC) program

BMC PALLIATIVE CARE | Online – 14 July 2020 – This study’s findings support the SPA-LTC program. Across four long-term care (LTC) sites, this program reduced hospital use at end of life (EoL), with significant reductions in emergency department use and hospital deaths. Both the quantitative and qualitative data from family interviews indicated that families who experienced a palliative care (PC) conference ... reported that these were helpful and provided support to them, and that they felt comfortable making EoL decisions for residents... The open-ended questions or qualitative findings elaborated on these responses by describing how PC conferences improved communication with healthcare providers and allowed them to feel “all on the same page.” Given these findings, it is quite likely that by attending a PC conference, families were able to address their questions and concerns and become informed so that they could feel more comfortable making decisions about EoL issues which contributed to the reductions in emergency department use and hospital death, allowing residents to remain in LTC until their death. **Full text:** <https://bit.ly/3fuk6xR>

Family meetings in paediatric palliative care: An integrative review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 July 2020 – Ten empirical studies and five theoretical articles were included in the synthesis. Empirical studies provided more information about meeting structure, whereas theoretical articles more frequently described a desired process for planning and undertaking meetings. No articles identified how the success of a meeting was defined or made recommendations for doing so. Despite reports that family meetings are commonly occurring, few articles described outcomes from either the family or clinician perspectives. Family meetings are essential communication strategies commonly used in paediatric palliative care (PC), yet there is little guidance about how meetings should be organised and conducted, who should participate and when they should occur. The limited data available on the outcomes of family meetings suggest improvements are required to meet the needs of families. The authors present a framework that synthesises the available evidence. The framework offers an overview of the elements to consider when planning for and undertaking family meetings in paediatric PC and may be useful for both clinicians and researchers. **Abstract:** <https://bit.ly/2WzIUyd>

Current collaboration between palliative care and neurology: A survey of clinicians in Europe

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 10 July 2020 – The collaboration between palliative care (PC) and neurology has developed over the last 25 years and this study aimed to ascertain the collaboration between the specialties across Europe. This online survey aimed to look at collaboration across Europe, using the links of the European Association for Palliative Care and the European Academy of Neurology. 298 people completed the survey – 178 from PC and 120 from neurology from over 20 countries across Europe. They reported that there was good collaboration in the care for people with amyotrophic lateral sclerosis and cerebral tumours, but less for other progressive neurological diseases. The collaboration included joint meetings and clinics and telephone contacts. All felt that the collaboration was helpful, particularly for maintaining quality of life, physical symptom management, psychological support and complex decision-making, including ethical issues. The study shows evidence for collaboration between PC and neurology, but with the need to develop this for all neurological illness, and there is a need for increased education of both areas. **Abstract:** <https://bit.ly/3iS7fHT>

Noted in Media Watch 20 January 2020 (#649, p.3):

- *NEUROLOGY*, 2018;91(5):217-226. **‘Neuropalliative care: Priorities to move the field forward.’** Neuropalliative care is an emerging subspecialty in neurology and palliative care (PC). In 2017, a Neuropalliative Care Summit was convened with national and international experts in the field to develop a clinical, educational, and research agenda to move the field forward. Clinical priorities included the need to develop and implement effective models to integrate PC into neurology and to develop and implement informative quality measures to evaluate and compare palliative approaches. Educational priorities included the need to improve the messaging of PC and to create standards for PC education for neurologists and neurology education for palliative specialists. **Abstract:** <http://bit.ly/2smjzuz>

What variables contribute to the achievement of a preferred home death for cancer patients in receipt of home-based palliative care in Canada?

CANCER NURSING | Online – 8 July 2020 – The objectives of this study were to measure the congruence between a preferred and actualized home death among cancer patients in receipt of home-based palliative care (PC) in Canada and explore predictors of actualizing a preferred home death. 290 caregivers were interviewed biweekly over the course of patients’ PC trajectory between July 2010 and August 2012. Home was the most preferred place of death, and 68% of patients who had voiced a preference for home death had their wish fulfilled. Care context variables, such as living with others and the intensity of home-based nursing visits and hours of care provided by personal support workers (PSW), contributed to actualizing a preferred home death. The intensity of emergency department visits was associated with a lower likelihood of achieving a preferred home death. This study has implications for policy decision-makers and healthcare managers. Improving and expanding the provision of home-based PSW and nursing services in palliative home care programs may help patients to actualize a preferred home death. **Abstract:** <https://bit.ly/2Oez2Eo>

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 10 July 2020 – **‘Caregiver-reported quality measures and their correlates in home hospice care.’** In this cross-sectional study, the authors found that caregiver comfort in managing patient symptoms during the last week on hospice was associated with all three quality measures examined: 1) Caregiver burden; 2) Caregiver satisfaction; and, 3) Quality of end-of-life care. They also found that both higher caregiver-reported symptom scores and caring for patients who did not die in hospice were associated with higher caregiver burden and lower satisfaction with care. This study reinforces the important relationship between the perceived suffering/symptoms of patients and caregivers’ hospice experiences. **Full text:** <https://bit.ly/2CGvFDP>

Cont.

Noted in Media Watch 20 April 2020 (#662, p.15):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 15 April 2020 – ‘**Congruence between preferred and actual place of death for those in receipt of home-based palliative care.**’ Understanding the factors that affect the congruence between preferred and actual place of death may help providers offer clients customized end-of-life care settings. Little is known about this congruence for cancer patients in receipt of home-based palliative care (PC). In this study, the overall congruence between preferred and actual place of death was 71.72%. Home was the most preferred place of death. The intensity of home-based nursing visits and hours of care from personal support workers increased the likelihood of achieving death in a preferred setting. **Abstract:** <https://bit.ly/3ekytom>

Noted in Media Watch 23 March 2020 (#658, p.7):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 March 2020 – “**‘I want to go home.’: How location at death influences caregiver well-being in bereavement.**’ Congruence between a dying person’s preferred and actual locations at death has been considered good care and may influence the quality of bereavement. Yet, the preferred location for end-of-life care may be unaddressed. There has been little focus on the reciprocity between caregiver-patient wishes. Discussing preferences about the place of end-stage care may not make location congruence possible, but it can foster shared understanding and support for caregivers’ sense of coherence and well-being in bereavement. **Abstract (w. list of references):** <http://bit.ly/2vZtV5D>

How many people need palliative care for cancer and non-cancer diseases in a middle-income country? Analysis of mortality data

COLOMBIAN JOURNAL OF ANESTHESIOLOGY | Online – 1 July 2020 – The numbers of deaths in Colombia requiring palliative care (PC) increased from 107,065 in 2012 to 128,670 in 2016 (61.2% of total deaths). The causes of these deaths varied by age group, with a clearly more important proportion of heart and cerebrovascular diseases and dementia in advanced ages, and HIV/AIDS in young ages. In all age groups, malignant neoplasms are an important part of the causes of deaths of those requiring PC – 31.3% of all deaths in 2016. Contrasting this need, in most areas there is no or very limited offer of PC services. A real PC policy, including a vast increase in training opportunities in the field and regulation allowing a wide range of health practitioners to be involved in PC, is necessary in Colombia to improve the availability of PC. **Full text (click on pdf icon):** <https://bit.ly/300V8zR>

Noted in Media Watch 29 June 2020 (#672, p.5):

- *HEALTH POLICY & PLANNING* | Online – 24 June 2020 – ‘**Strategies used to establish palliative care in rural low- and middle-income countries: An integrative review.**’ Despite the inclusion of palliative care (PC) in national health policy in some countries, implementation in the community was often reliant on advocacy and financial support from non-government organizations. Training, role play, education and mentorship were strategies used to support health providers and volunteers. Home- and community-based PC services for rural low- and middle-income countries communities may best be delivered using a networked service among health professionals, community volunteers, religious leaders and technology. **Abstract:** <https://bit.ly/383nT2j>

Will they let me die? Perspectives of older Swiss adults on end-of-life issues

DEATH STUDIES | Online – 14 July 2020 – This article contributes to scientific discussion with regard to the interplay of individual and social factors on end-of-life (EoL) decisions. Semi-directed interviews with people over 65 years highlighted two different but articulated fears in relation to EoL care: on one hand, older adults fear not being allowed to die and being subjected to therapeutic obstinacy; on the other, they fear not being cared for properly, due to their age and a lack of financial resources in the health and social care system. Recommendations are given to assist professionals in discussing these fears with the people concerned and their families. **Abstract:** <https://bit.ly/2Wj4rdr>

COVID-19, palliative care and public health

EUROPEAN JOURNAL OF CANCER, 2020; 136(9):95-98. The lack of integration between public health approaches, cancer care and palliative and end-of-life care (EoLC) 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 (PC) and to global health may allow it to be a demonstration model for how the problem of integration can be addressed. Before the pandemic, the large majority of individuals with cancer in need of PC in low- and middle-income countries and the poor or marginalised in high-income countries were denied access. This inequity was highlighted by the COVID-19 pandemic, as individuals in impoverished or population-dense settings with weak health systems have been more likely to become infected and to have less access to medical care and to palliative and EoLC. Such inequities deserve attention by government, financial institutions and decision-makers in healthcare. However, there has been no framework in most countries for integrated decision-making that takes into account the requirements of public health, clinical medicine and palliative and EoLC. Integrated planning across these domains at all levels would allow for more coordinated resource allocation and better preparedness for the inevitability of future systemic threats to population health. **Abstract (w. list of references):** <https://bit.ly/2OhlJTG>



Palliative and end-of-life care in the context of the COVID-19 pandemic

A selection of recent journal articles, with links to full-text, can be viewed on the European Association for Palliative Care blog at: <https://bit.ly/3iZKjXr>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 July 2020 – ‘Upside down solutions: Palliative care and COVID-19.’ The phrase upside down may point towards dynamic solutions to arm the palliative care (PC) community to better tackle this crisis. This article explores how the field can contribute by ensuring that PC principles and practices are woven into everyday healthcare practice. The authors explore alternative ways of providing care under such pressure and discuss three areas of learning from resource-limited settings: 1) Integration of palliative medicine into everyday practice; 2) Simplification of biomedical management plus multidisciplinary teamwork; and, 3) Effective use of volunteers. **Full text:** <https://bit.ly/3ignvma>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 July 2020 – ‘Virtual visits in palliative care: About time or against the grain?’ Has the use of remote consulting only been effective because there has been no better alternative during the pandemic or has this simply been an expedited process of both practical and cultural change in working practices that was bound to happen over time anyway? The authors feel that they have an idea of the positive contributions remote consulting has made, but are there more complex issues with the long-term use...? A “one-size-fits-all” mentality is a poor fit for the individualised needs of the heterogeneous PC population. Virtual visits have great potential even if they are not a panacea. **Full text:** <https://bit.ly/397XhxH>

N.B. A selection of articles from past issues of Media Watch on telehealth are noted in the current issue of the newsletter of the International Association for Hospice & Palliative Care. **Download/view at (scroll down to ‘Media Watch: Telehealth’):** <https://bit.ly/2ZO16DZ>

Cont.

- *BRITISH MEDICAL JOURNAL* | Online – 15 July 2020 – ‘**COVID-19: Government to issue new guidance on DNAR orders after legal challenge.**’ The government ... will publish new national guidance for England on “do not attempt resuscitation” orders, amid concern that blanket bans on CPR were being imposed by some healthcare providers during the COVID-19 pandemic. The move comes after a threat of legal action against the government by the daughter of a man who successfully fought to establish that patients have a right to be consulted on resuscitation. In May she launched a High Court challenge against the health secretary over the government’s failure to issue clear national guidance to ensure that patients’ rights in relation to DNARs were protected. **Full text:** <https://bit.ly/2Wkoqlo>
- *BRITISH MEDICAL JOURNAL* | Online – 14 July 2020 – ‘**Palliative care for patients with severe COVID-19.**’ Many patients with severe COVID-19 experience distressing symptoms... Palliation of suffering is an important part of care irrespective of prognosis. Patients with severe COVID-19 may deteriorate rapidly. It is therefore useful to have a strategy in place for managing deterioration and potential death (for those not suitable for escalation to intensive care), which runs alongside the acute medical management plan. Clear and timely communication with the patient (if they are able) and their carers is essential. Conveying hope that treatments will help needs to be sensitively balanced with explicit acknowledgement that patients are sick enough to die. **Full text:** <https://bit.ly/3fwPzQe>
- *EUROPEAN RESPIRATORY JOURNAL* | Online – 16 July 2020 – ‘**COVID-19: Guidance on palliative care from a European Respiratory Society international task force.**’ This multinational task force provides consensus recommendations for palliative care (PC) for patients with COVID-19 concerning: advance care planning; palliative treatment of breathlessness; clinician-patient communication; remote clinician-family communication; PC involvement in patients with serious COVID-19; spiritual care; psychosocial care; bereavement care; and support for healthcare professionals. The fact that 13 out of 14 questions achieved recommendations above 70% in the first round shows that there is a need to consider PC in the treatment of COVID-19 or similar diseases. **Full text:** <https://bit.ly/395CRoV>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 July 2020 – ‘**A view from the frontline: Palliative and ethical considerations of the COVID-19 pandemic.**’ The pandemic has highlighted the role of primary and specialty palliative care (PC) in the ICU... The availability of specialty PC to meet the needs of critically ill patients varies tremendously across healthcare systems and shapes the balance of the two types of PC. The pandemic has reinvigorated strategies to address goals of care before hospitalization and/or ICU admission among high-risk populations. Families and clinicians have been forced to adapt to the dynamic ICU environment during the pandemic, but the perseverance and sense of community in the face of seemingly insurmountable odds are evident. **Full text:** <https://bit.ly/2ZAYzhm>
- *PALLIATIVE MEDICINE* | Online – 17 July 2020 – ‘**The Palliative Performance Scale predicts mortality in hospitalized patients with COVID-19.**’ In this study of 443 patients, the authors determined the Palliative Performance Scale (PPS) score for 374. Overall mortality was 31% and 81% in intubated patients. In all, 36% of patients had a low PPS score. Compared with patients with a high score, patients with a low score were more likely to die, have do not intubate orders, and be discharged to a facility. The PPS independently predicts mortality... Improved predictors of mortality can help clinicians caring for patients with COVID-19 to discuss prognosis and provide appropriate palliative care including decisions about life-sustaining therapy. **Abstract (w. list of references):** <https://bit.ly/3je9qpu>

How is early palliative care defined and implemented for persons diagnosed with a life-limiting chronic illness: A scoping review protocol

JBI EVIDENCE SYNTHESIS | Online – 6 July 2020 – Globally, the prevalence of life-limiting chronic illnesses, such as cardiovascular diseases, cancer, respiratory diseases, and diabetes, have surpassed infectious diseases and are now the leading cause of death in adults. In 2011, it was estimated that over 29 million individuals died from chronic, life-limiting conditions that would be appropriate for palliative care (PC), such as dementia, cancer, cardiovascular diseases, liver cirrhosis, chronic obstructive lung disease, diabetes, HIV/AIDS, kidney failure, multiple sclerosis, and Parkinson’s disease. PC is a term that has been refined in recent years in response to changing societal views of end-of-life care. The term originated within hospice settings, which focus on patients who are terminally ill (i.e., prognosis of living less than six months) and are no longer seeking disease-altering treatments, and continues to be conflated. This definition is problematic as modern PC has evolved into a broader concept that extends beyond hospice care offered near death. This misunderstanding of PC has perpetuated ongoing stigma and created barriers to effective utilization of PC services. **Full text (click on pdf icon):** <https://bit.ly/2OOhmBHR>

Children's views are not taken into account in accordance with Article 12 of the United Nations Convention on the Rights of the Child in the Family Talk Intervention when a parent is cared for in palliative care

OMEGA – JOURNAL OF DEATH & DYING | Online – 12 July 2020 – Having a parent with a life-threatening illness is challenging throughout the illness trajectory, and for some also in bereavement. Article 12 of the United Nations Convention on the Rights of the Child states a child's right to express their opinion and have it respected in processes that affect them. The aims of this article were to explore the child's active participation in a family support programme, the Family Talk Intervention, in accordance with Article 12, when having a parent cared for in palliative care (PC). Twenty families with 50 children participated. Field notes were taken during the programme and later analysed with interpretive descriptions. The study shows that all children were listened to, but only a quarter reached the minimum point required in Article 12, where their views were taken into account. The Family Talk Intervention in PC would benefit from implementing a child-centred approach in order for all children to be active participants. **Abstract (w. list of references):** <https://bit.ly/32eFV0G>

Noted in Media Watch 4 June 2018 (#566, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 29 May 2018 – ‘**Researching children's perspectives in pediatric palliative care: A systematic review and meta-summary of qualitative research.**’ The authors retrieved 16 qualitative research articles reporting on 12 unique studies, and they selected two mixed-method articles. The meta-summary shows eight themes: 1) The relationship with professional caregivers; 2) Pain and its management; 3) “Living beyond pain,” 4) The relationship between pediatric patients and their families; 5) Children's view on their treatment and service provision; 6) Meanings children give to their end-of-life situation; 7) Consequences of clinical decisions; and, 8) The relationships among children in pediatric PC and their peers. **Abstract (w. list of references):** <https://bit.ly/3emCxDu>

N.B. Selection of articles on children's participation in advance care planning noted in Media Watch 21 October 2019 (#636, p.6). Additional articles on the “child's voice” in the context of end-of-life care noted in Media Watch 9 October 2017 (#533, pp.6-7).

Music as consolation: The importance of music at farewells and mourning

OMEGA – JOURNAL OF DEATH & DYING | Online – 12 July 2020 – In this study, the authors examined a case where twelve participants conducted farewell ceremonies for their deceased relatives. Taking a qualitative approach, they used interviews and questionnaires to focus on life stories that involve grieving. Specifically, we asked about experiences of the grief process as related to choice of music. The authors results indicate that the role of music in farewell rituals is important for the grieving process in several ways. Firstly, music was associated with positive memories of the loved one and gave rise to experiences of recognition. Secondly, music facilitated active participation in the grieving process through choosing farewell music together with a relative. Thirdly, selecting music for the funeral in advance, together with their loved ones, was also experienced as hopeful, comforting and consoling before, during and after the bereavement. **Abstract (w. list of references):** <https://bit.ly/3fqgtcm>



[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/2RPPJy9b>

What would people think? Perceived social norms, willingness to serve as a surrogate, and end-of-life treatment decisions

PALLIATIVE & SUPPORTIVE CARE | Online – 15 July 2020 – The authors investigated how intrapersonal and social-contextual factors predicted two components of the surrogate decision-making process: individuals' willingness to serve as a surrogate and their tendency to select various end-of-life (EoL) treatments, including mechanical ventilation and palliative care options. Viewing service as a surrogate as a more typical practice in healthcare was associated with greater willingness to serve. Greater decision-making confidence, greater willingness to collaborate with patients' physicians, and viewing intensive, life-sustaining EoL treatments (e.g., mechanical ventilation) as more widely accepted were associated with choosing more intensive EoL treatments. This study's consideration of both intrapersonal and social-contextual factors advances knowledge of the two key aspects of surrogate decision-making... Providers can use information about the role of these factors to engage with surrogates in a manner that better facilitates their decision-making. For instance, providers can be sensitive to potential cultural differences in surrogate decision-making tendencies or employing decision aids that bolster surrogates' confidence in their decisions. **Abstract (w. list of references):** <https://bit.ly/2AYWe6u>

Noted in Media Watch 25 May 2020 (#667, p.8):

- *JAMA NETWORK OPEN* | Online – 19 May 2020 – '**Assessment of discordance between surrogate care goals and medical treatment provided to older adults with serious illness.**' Almost half of the patients in this study had at least one medical treatment or code status order that was discordant with the goal of care identified by their surrogates. The most common source of discordance was having a full code status when the surrogate's preferred goal was comfort measures only or an intermediate goal. There may be many cases where needed discussions with the surrogate do not occur or result in an order change. This study found there may be serious consequences to failing to document preferences for comfort care. **Full text:** <https://bit.ly/2XaaLDw>

N.B. Selected articles on surrogate decision-makers noted in Media Watch 6 April 2020 (#660, p.8).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *SWISS MEDICAL WEEKLY* | Online – 1 July 2020 – '**Social, cultural and experiential patterning of attitudes and behaviour towards assisted suicide in Switzerland: Evidence from a national population-based study.**' Switzerland has the longest history of the legal practice of non-physician assisted suicide of any country. Assisted suicide is not very tightly regulated in Switzerland, and almost all assisted suicides are supported by a right-to-die organisation. This study investigates older adults' attitudes and behaviour towards assisted suicide, and the associations of these with the individuals' socio-demographic and cultural characteristics, as well as with their own health status and healthcare-related experiences in Switzerland. While approval for assisted suicide is high overall in Switzerland, more vulnerable population groups, such as older or less educated individuals, have less favourable attitudes towards assisted suicide. In addition, cultural sensitivities to and personal experiences with death and dying are likely to shape the approval or rejection of assisted suicide as it is currently implemented in Switzerland. **Full text:** <https://bit.ly/2DET2xZ>

Extract from *Swiss Medical Weekly* article

Assisted suicide is widely reported in the Swiss media, whereas information about palliative care, advance directives and other forms of end-of-life (EoL) planning is discussed less often. There are significant knowledge gaps among the population regarding different EoL options.

Publishing Matters

Is intentional publishing in predatory journals a form of scientific misconduct?

SOUTH AFRICAN JOURNAL OF BIOETHICS & LAW, 2020;13(1):57-61. Predatory journals are widely acknowledged as a significant problem in scholarly publishing and, more broadly, as a threat to the responsible conduct of research. Because predatory publishers base their operations on deception, it is possible for well-intentioned researchers to unwittingly end up publishing their work in predatory journals. Of a more problematic nature is the behaviour of researchers who intentionally publish in predatory journals as a way of bypassing legitimate peer-review. In such cases it is important to decide what such behaviour constitutes as a way of developing policy aimed at deterrence. The aim of this study was to answer the question of whether intentional publishing in predatory journals can be considered a form of scientific misconduct, based on the critical application of four conditions taken as being requirements for this. It is not currently possible to satisfy all four conditions that would include intentional predatory publishing as a form of scientific misconduct. However, there are grounds to argue that this behaviour satisfies the definition of a questionable research practice. Regardless of exactly where intentional predatory publishing is placed in the spectrum of unethical research behaviours, there is an urgent need for coherent institutional policy to effectively deal with it and, more broadly, naïve publishing in predatory journals.

Full text (click on pdf icon): <https://bit.ly/2ZVjdru>

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

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

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

Canada



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

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

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

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://bit.ly/3iZKjXr>

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

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

South America

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

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