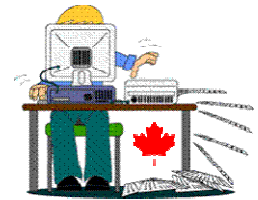


Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Pros and cons of telehealth/telemedicine in end-of-life care: Scroll down to [Specialist Publications](#) and 'Mobile health technology and home hospice care: Promise and pitfalls' (p.14), in *Progress in Palliative Care*.

[Canada](#)

Nurses union urges action on long-term care staffing

MANITOBA | *The Winnipeg Free Press* – 26 April 2018 – The Manitoba Nurses Union (MNU) is renewing calls for the province to legislate minimum staffing at personal care homes. An MNU report¹ ... sounds the alarm about nursing shortages, patients with increasingly more complex and chronic needs, and what the union says is the inadequate funding of long-term care (LTC). Although the union has published several similar reports in the past, president Sandi Mowat said this one originated last fall after long-term-care nurses began raising concerns about not having enough time to spend with their patients. Those concerns escalated last month when the Manitoba government announced funding for LTC services in 2018-2019 at \$644.3 million, a drop of \$2.3 million from the previous year. Of the more than 500 LTC nurses surveyed, 64% believed there had been “very few to no improvements” in their facility when it came to care quality and 56% said they didn’t think staffing levels were adequate. Further to that, the report says nurses spoke of a “perceived reluctance from the employer to address chronic nursing shortages.” The union is laying out six recommendations for the government, including amending staffing guidelines and legislating them so they are stronger. <https://goo.gl/sk1r19>

1. 'The Future of Long-Term Care is Now: Addressing nursing care needs in Manitoba's Personal Care Homes, Manitoba Nurses Union, April 2018. **Download/view at:** <https://goo.gl/TqX5qU>

Noted in Media Watch 31 July 2017 (#523, p.8):

- *CANADIAN JOURNAL ON AGING* | Online – 27 July 2017 – ‘**Broadening end-of-life comfort to improve palliative care practices in long term care.**’ This study explores how palliative care (PC) in long-term care (LTC) addresses the tensions associated with caring for the living and dying within one care community, and to inform how PC practices may be improved to better address the needs of all residents living and dying in LTC as well as those of the families and support staff. Eliciting residents’ perceptions of end of life (EoL) comfort, sharing information about a fellow resident’s death more personally, and ensuring that residents, families, and staff can constructively participate in providing comfort care to dying residents could extend the purview of EoL comfort and support expanded integration of palliative principles within LTC. **Abstract (inc. list of references):** <https://goo.gl/ZhGxvo>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | *The National Post* (Halifax) – 23 April 2018 – ‘**Can we die? The seriously ill need clarity.**’ More than 2,000 people have died with the help of a doctor since Canada’s new medical assistance in dying (MAiD) law, Bill C-14, received royal assent in June 2016. This legislation has, however, come under sustained criticism for its ambiguity. When it was first introduced, concerns were immediately expressed about the eligibility criterion that “natural death has become reasonably foreseeable.” This phrase “reasonably foreseeable” was deemed by many to be unfamiliar and unclear for physicians and their regulators. It has led to confusion and a variety of interpretations among providers and assessors of MAiD. Now the Nova Scotia College of Physicians & Surgeons has developed a statement that clarifies this criterion.¹ This will remove a barrier to access to MAiD for some seriously ill patients in the province... <https://goo.gl/hm3mbw>

1. ‘Professional Standard Regarding Medical Assistance in Dying,’ Nova Scotia College of Physicians & Surgeons. **Download/view at:** <https://goo.gl/EJnBsG>

U.S.A.

Family caregivers finally get a break – and some coaching

NATIONAL PUBLIC RADIO | Online – 27 April 2018 – Across the country, community groups, hospitals, government agencies and non-profits are starting to do more to support at least some of the estimated 42 million friends and family members who are the primary caregivers of adults and children who have disabilities, are recovering from surgeries and illnesses or are coping with Alzheimer’s and other chronic diseases. A bipartisan law ... calls for a national strategy to address the needs of caregivers, who are primarily women and provide 37 billion hours in unpaid care to relatives or close friends. All those hours are valued at \$470 billion... The law will require the Department of Health & Human Services to set up an advisory council and develop a blueprint for government action on financial and workplace issues, respite care and other caregiver issues. At the same time, 42 states and the District of Columbia have passed their own laws requiring hospitals and other nursing facilities to provide training for caregivers who perform medical tasks, and to record them as the “caregiver” when patients are admitted or released from hospitals or nursing facilities. In states without such a law (Alabama, Florida, Georgia, Idaho, South Carolina, South Dakota, Vermont and Wisconsin (Kansas’ law takes effect in July) – patients can be dismissed from the hospital without family members being told or briefed fully on what care the patient needs. <https://goo.gl/Gs253x>

Specialist Publications

‘**Responding to those who hope for a miracle: Practices for clinical bioethicists**’ (p.6), in *American Journal of Bioethics*.

‘**Assisted suicide/aid in dying: What is the nurse’s role?**’ (p.14), in *American Journal of Nursing*.

Death is not a failure: Medical schools adapt end-of-life lessons

MASSACHUSETTS | Associated Press (Boston) – 24 April 2018 – Local medical schools are in the process of a curricula revamp that will train students to focus more on end-of-life care, making Massachusetts the first in the nation to reach a state-wide commitment to quality of life. The Massachusetts Coalition for Serious Illness Care has orchestrated the effort among four local institutions: Harvard Medical School, Boston University School of Medicine, Tufts University School of Medicine, and University of Massachusetts Medical School. <https://goo.gl/CtngbR>

Cont.

Noted in Media Watch 19 February 2018 (#551, p.3):

- MASSACHUSETTS | *Kaiser Health News* (Boston) – 12 February 2018 – ‘**Doctors learn how to talk to patients about dying.**’ Hundreds of clinicians at Massachusetts General Hospital in Boston are getting trained to talk to seriously ill patients about their goals, values – and prognoses – while there’s time to spare. At the hospital, Dr. Juliet Jacobsen, a palliative care physician, serves as medical director for the Continuum Project, a large-scale effort to quickly train clinicians to have these conversations, document them and share what they learn with one another. <https://goo.gl/wd6ge4>

Barbara Bush and the problem with “comfort care”

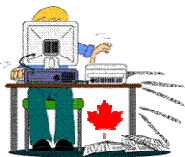
PENNSYLVANIA | *The Inquirer* (Philadelphia) – 24 April 2018 – Two days before she died, former first lady Barbara Bush announced through a family spokesman that, in light of her failing health, she would not seek additional medical treatment, opting instead for “comfort care.” Scouring Twitter after the announcement, I found that most tweets expressed sorrow, largely because Mrs. Bush was electing comfort care and that meant that she would die imminently. Many other tweets lauded her choice of comfort care, noting how brave she was to stop treating her illness. Both of these sentiments reflect the language problem that doctors and patients have at the end of life. When physicians such as me divide care into “medical treatment” and “comfort care,” we ignore that we should focus on both comfort and medical treatment at the same time. Medicare policy reinforces the divide between medical care and comfort care. For example, patients must forgo curative treatment (such as chemotherapy) if they choose to enroll in hospice. As an oncologist, I see on a daily basis how this language problem makes it harder for doctors to do what’s best for our patients. <https://goo.gl/B6SKbE>

N.B. Additional articles on the language and terminology of care for patients and family living with a terminal illness noted in the 23 April 2018 issue of Media Watch (#560, p.11).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | CBS13 News (Sacramento) – 26 April 2018 – ‘**No death with dignity: Veterans home members face eviction over end-of-life option.**’ California veterans living in eight veterans homes could face eviction if they seek a medication that is legal for everyone in the state. The California Veterans Affairs Department is banning the so-called “death with dignity option” on their campuses because the homes receive federal funding and the option is not a federal law. <https://goo.gl/ssLkhA>
- DELAWARE | *Delaware State News* (Dover) – 26 April 2018 – ‘**Assisted suicide bill removed from agenda again.**’ The House of Representatives did not vote on a controversial assisted suicide bill, the second time in three months the measure has been yanked from the agenda. House Bill 160 [i.e., the Delaware End of Life Options Act], was pulled from the agenda because at least one legislator backed off, bringing the side in favor to fewer than 21 votes. The same thing happened in January. The measure carries several safeguards, such as requiring a doctor to confirm the individual in question is dying and is not suffering from any mental illness or condition. It also mandates the patient request the medication three times and imposes a 15-day waiting period between the first and second oral request and a two-day delay between the final request and the writing of the prescription. <https://goo.gl/VFngX>



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://goo.gl/5CHoAG>

International

Treatment for cancer? No thanks, say some patients

SINGAPORE | *Today* – 28 April 2018 – Medical advances have made many cancers highly treatable or potentially curable, especially when detected early, but it is not uncommon for doctors to meet patients who refuse standard treatments. One in five patients might decline treatment when they first see a cancer doctor due to various reasons, estimated medical oncologist Ravindran Kanesharan of the National Cancer Centre Singapore. Some patients opt to rely on the power of their faith, while others hold negative views of standard treatments and think they will end up worse off as a result. Family members and caregivers are sometimes the barrier to treatment, while others reject the option due to depression. Although doctors strive to provide the right information to those afflicted with cancer, treatment decisions are highly personal and patients' wishes should be respected, they said. While most patients who refuse treatment are in the terminal stages of the disease, this is not always so, said Dr. Teoh Ren Shang, a senior resident physician at the Singapore Cancer Society's hospice care services... Some patients also believe treatment for cancer causes more harm than good, and may prefer to rely on complementary and alternative medicine (CAM), said Dr. Teoh. He estimated that at least half of the patients he saw last year who required palliative care used a combination of CAM and medication. <https://goo.gl/muJZkJ>

Alfie Evans dies at Alder Hey hospital after life support withdrawn

U.K. (England) | *The Guardian* (London) – 28 April 2018 – A 23-month-old boy with a rare degenerative brain disease who was at the centre of a protracted legal battle has died... Alfie Evans died at Alder Hey children's hospital in Liverpool in the early hours of Saturday morning. Life support was withdrawn on Monday after a last-ditch appeal to the high court was turned down. Alfie had been in a semi-vegetative state and scans of his brain had shown that almost all of it had been destroyed. Judges had agreed with doctors that further treatment would be futile and there was no hope of him getting better. His parents ... had insisted their son was not in pain or suffering, but lost cases in the high court, court of appeal, supreme court and European court of human rights. <https://goo.gl/NgwmWr>

Related

- U.K. (England) | ITV (London) – 25 April 2018 – **'How do medics reach decisions in cases like that of Alfie Evans?'** The court battle over the treatment of Alfie Evans has seen his parents in dispute with medics treating their child. Judges have had to weigh up complicated issues in reaching their decisions. Here, experts answer some of the questions related to such cases. <https://goo.gl/y2RLvH>

N.B. Earlier news media coverage of the Alfie Evans case noted in the 16 April 2018 issue of Media Watch (#559, p.3).

Specialist Publications

'Developing compassionate communities in Australia through collective caregiving: A qualitative study exploring network centred care and the role of the end of life sector' (p.7), in *Annals of Palliative Medicine*.

'How to explore the end-of-life preferences of homeless people in the U.K.' (p.10), in *European Journal of Palliative Care*.

'Palliative care in humanitarian crises: A review of the literature' (p.11), in *Journal of International Humanitarian Action*.



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.15.

Step-change needed in support for carers of terminally ill, argue academics

U.K. (England) | University of Manchester – 24 April 2018 – A new report urges healthcare providers to radically improve the way they support carers of people approaching the end of their life.¹ The report, by Dr. Gail Ewing from the University of Cambridge and Professor Gunn Grande from the University of Manchester, argues a major cultural shift among staff is desperately needed to help carers. Improvements in structures and internal processes are also among the 10 recommendations in the National Institute for Health Research & Hospice UK funded report to improve the way healthcare organisations – such as hospices, hospitals, community nursing and general practice – to support carers' needs. The report, which was written following work with carers and clinical staff, highlights how family members often play a pivotal role in supporting their loved ones at the end of their life. And that, say the academics, provides more care at home and easing pressure on hospitals. <https://goo.gl/r76G8q>

1. 'Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change,' University of Cambridge & University of Manchester, April 2018. **Download/view at the Hospice UK website:** <https://goo.gl/3UQhAx>

Noted in Media Watch 5 March 2018 (#553, p.5):

- *PALLIATIVE MEDICINE* | Online – 28 February 2018 – '**Who cares for the carers at hospital discharge at the end of life?**' Enabling successful discharge of palliative care patients to home and prevention of readmissions is a key issue for health services. To date, the focus of interventions to achieve this outcome has been on patients. This study shifts the focus of discharge planning to include whether and in what way the support needs of carers might be assessed and addressed during the transition to home care. It offers a new direction for intervention development for hospital discharge to improve support for carers over the transition to home and prevent breakdown of care at home which is often a cause of readmission of patients to hospital. **Full text:** <https://goo.gl/GxLrzV>

Dutch hospitals check “vulnerability” of elderly patients before operating

THE NETHERLANDS | DutchNews.nl (Amsterdam) – 23 April 2018 – Two Dutch hospitals have begun assessing the “vulnerability” of patients over the age of 70 who are admitted to their emergency departments to determine their suitability for major operations and other far-reaching treatment... Doctors are using a short list of questions to determine if the elderly patient is fit enough to go through the procedure and will recover well. The questions cover issues such as medication, memory loss and whether or not the person concerned lives independently. The answers allow doctors to decide if a patient risks either dying or deteriorating when they are sent home after treatment. The Leiden University Medical Centre teaching hospital and the Haga hospital in The Hague are pioneering the

new system. It was developed after researchers noticed that 10% of the over 70s treated in the university's accident and emergency (A&E) department died within three months and a further 20% were no longer able to live independently. Last year, 800,000 people over the age of 65 ended up in an A&E department, and 530,000 of them were hospitalised. <https://goo.gl/v5FyKz>

[Specialist Publications](#)

'Living longer than expected: Admitted to a hospice with an underestimated life expectancy' (p.13), in *Nederlands Tijdschrift Voor Geneeskunde*.

Palliative Care Network

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/viewed at: <https://goo.gl/YLckx6>

Updated 04.28.2018

Specialist Publications

Drug consumption and futile medication prescribing in the last year of life: An observational study

AGE & AGEING | Online – 23 April 2018 – Hospital physicians have an opportunity to prioritize essential medications and de-prescribe potentially futile medications. The mean age of participants in this study was 80.8; 49.3% were female, and 63.7% were severely frail. The median number of days spent in hospital in the last year of life was 32... During all hospitalizations, the mean number of individual medications consumed was 23.8... One-in-six patients consumed 35 or more medications in their last year. Over 80% of patients were prescribed at least one potentially inappropriate medication at discharge... **Abstract:** <https://goo.gl/s6Fpbv>

Noted in Media Watch 18 September 2017 (#530, p.10):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 September 2017 – **‘Continuation of non-essential medications in actively dying hospitalised patients.’** Non-essential medications continue to be administered to actively dying patients. Orders for one or more non-essential medications were less likely to occur in association with palliative care consultation, do-not-resuscitate orders and orders for death rattle medication. Patients who died in an intensive care unit were more likely to receive a non-essential medication, as were older patients. **Abstract:** <https://goo.gl/jVWDzF>

N.B. Additional articles on the discontinuation of potentially inappropriate medications at the end of life noted in the 20 February 2017 issue of Media Watch (#500, p.14).

Responding to those who hope for a miracle: Practices for clinical bioethicists

AMERICAN JOURNAL OF BIOETHICS, 2018;18(5):40-51. Significant challenges arise for clinical care teams when a patient or surrogate decision-maker hopes a miracle will occur. This article answers the question, “How should clinical bioethicists respond when a medical decision-maker uses the hope for a miracle to orient her medical decisions?” The authors argue the ethicist must first understand the complexity of the miracle-invocation. They provide a taxonomy of miracle-invocations that assist the ethicist in analyzing the invocator’s conceptions of God, community, and self. After the ethicist appreciates how these concepts influence the invocator’s worldview, she can begin responding to this hope with specific practices. The authors discuss these practices in detail and offer concrete recommendations for a justified response to the hope for a miracle. **Abstract:** <https://goo.gl/3Qbwj8>

N.B. There are several commentaries on ‘Responding to those who hope for a miracle...’ in this issue of the journal. Contents page: <https://goo.gl/esZ2e7>. Additional articles on the subject noted in the 16 October 2017 issue of Media Watch (#534, p.12).

Journal Watch

‘Opportunistic journals in the clinical pharmacology space: A policy statement from the Publications & Public Policy Committees of the American College of Clinical Pharmacology’ (p.15), in *Clinical Pharmacology in Drug Development*.

‘Cabells’ journal whitelist and blacklist: Intelligent data for informed journal evaluations’ (p.15), in *Learned Publishing*.

Palliative Care Network

Closing the Gap Between Knowledge & Technology

<http://goo.gl/OTpc8I>

Developing compassionate communities in Australia through collective caregiving: A qualitative study exploring network centred care and the role of the end of life sector

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 23 April 2018 – The new public health palliative care (PC) movement calls for a move away from an individualised model of caregiving to a whole of community approach which will increase expectations on community carers. In order to avoid carer isolation, exploitation and potential burnout there is then a very real need to understand environments and relationships which support collective community caregiving. The authors explored in-home caring networks to understand if and how network centred care supports carers of the dying while developing a whole of community approach. Over a 6-year period researchers spoke to 301 caregivers, service providers and community members via interviews and focus groups in regional, rural and urban Australia. People are already caring for their dying at home and doing it well provided they are comprehensively supported by networks of care. Being part of a caring network provided people with a sense of achievement and developed their death literacy which flowed into a myriad of other community activities. While caring networks are essential they are not widely supported by service providers. At worst, services are obstructive of peoples stated preferences for place of death and caring and often adopt a paternalistic approach. Place of care, in this case the home, was supportive of maintaining networks and peoples' wellbeing. Operationalising public health approaches to PC requires moving to a place-based network centred model of care comprising formal and informal carers. Service systems need re-orienting to place caring networks as central to the caregiving process. **Abstract:** <https://goo.gl/GPwvaQ>

Related

- *SOCIOLOGY OF HEALTH & ILLNESS* | Online – 27 April 2018 – “‘Ingredients’ of a supportive web of caring relationships at the end of life: Findings from a community research project in Austria.” Although public discourse in western societies is dominated by questions about optimising specialised palliative care services, public health approaches, which take into account social determinants and inequalities in end-of-life care, have gained in importance over the last decade. The authors' focuses on the preconditions of a supportive caring web in order to understand how communities can build on their social capital to deal with existential uncertainty. **Full text:** <https://goo.gl/p6GDsM>

Caring communities as collective learning process: Findings and lessons learned from a participatory research project in Austria

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 23 April 2018 – The authors' analysis of qualities of a caring community, from the perspective of community members, highlights the importance of the co-creation of supportive care relationships in the local care web, through everyday life solidarity in the neighbourhood, appreciating and exchanging the wisdom of care, and also marked the role of professionals as enablers. **Abstract:** <https://goo.gl/KUSYNn>

All with you: A new method for developing compassionate communities – experiences in Spain and Latin-America

ANNALS OF PALLIATIVE MEDICINE | Online – Accessed 23 April 2018 – The 'All with you' method has been developed as a systematic approach that enables anyone interested in building compassionate communities or cities to include all of the elements outlined in the Compassionate City Charter.¹ Several cities in Spain and Latin America have already joined the movement of compassionate cities using this method, including four in Spain, four in Colombia and one in Argentina. **Abstract:** <https://goo.gl/p14Hr8>

1. Compassionate City Charter: <https://goo.gl/2znSNB>

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Noted in Media Watch 12 February 2018 (#550, p.10):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 10 February 2018 – ‘**Carer experience of end-of-life service provision: A social network analysis.**’ The results of the authors’ analysis revealed the relatively marginal positioning of formal service providers as perceived by informal networks. Despite these perceptions, opportunities arose in end-of-life caring to build networks of support among family, friends, community and service providers. However, when palliative care practice focuses on actions for the physical comfort of the dying person and possibly their principal carers, and informal networks are preoccupied with relationships, there is a separation of agency and communion that is detrimental to the growth of social capital. **Full text:** <https://goo.gl/Q6XChL>

N.B. Additional articles on “compassionate communities” and carer’s support networks noted in the 9 October 2017 and 26 February 2018 issues of Media Watch (#533, p.12 and #552, p.4, respectively). Of related interest is palliative and end-of-life care from a public health perspective: see the 13 June 2016 and 27 February 2017 issues of Media Watch (#466, p.14 and #501, pp.8-9, respectively).

Ethics of end-of-life decisions in pediatrics: A narrative review of the roles of caregivers, shared decision-making, and patient centered values

BEHAVIORAL SCIENCES | Online – 26 April 2018 – While a paternalistic approach is typically applied to children with life-limiting medical prognoses, the cognitive, language, and physical variability in this patient population is wide and worthy of review. In end-of-life (EoL) discussions in pediatrics, the consideration of a child’s input is often not reviewed in depth, although a shared decision-making model is ideal for use, even for children with presumed limitations due to age. This narrative review of EoL decision-making in pediatric care explores nomenclature, the introduction of the concept of death, relevant historical studies, limitations to the shared decision-making model, the current state of EoL autonomy in pediatrics, and future directions and needs. Although progress is being made toward a more uniform and standardized approach to care, few non-institutional protocols exist. Complicating factors in the lack of guidelines include the unique facets of pediatric EoL care, including physical age, paternalism, the cognitive and language capacity of patients, subconscious influencers of parents, and normative values of death in pediatrics. **Full text:** <https://goo.gl/Py1bVH>

N.B. See ‘Paediatric palliative care: The patient’s voice,’ *European Journal of Palliative Care*, 2018;25(1): 19. Access requires a subscription. January/February issue contents page: <https://goo.gl/6MW3xN>

Related

- *CHILDREN* | Online – 26 April 2018 – ‘**From inpatient to clinic to home to hospice and back: Using the “Pop Up” pediatric palliative model of care.**’ An emerging model of care known as “Pop Up” describes the approaches to supporting children and young people in any facility. A Pop Up is a specific intervention over and above the care that is provided to a child, young person and their family aimed at improving the confidence of local care providers to deliver ongoing care. The authors look at some of the factors related to care transfer for pediatric palliative patients from one care facility to another, home and the impact of this on the family and medical care. **Full text:** <https://goo.gl/sz6CW4>
- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2018;25(2):56-58. ‘**An urgent call for collaboration: The future of research in paediatric palliative care.**’ The service models for paediatric palliative care (PPC) vary across Europe, with 11.6% of countries having these services integrated with mainstream services and 32.6% having no known PPC services. The U.K. has had PPC services for more than 30 years, but these have grown in a very organic way, without a good evidence base for the interventions, care and services given to the children and their families. This is highlighted in the evidence available to produce the recent National Institute for Health & Care Excellence guidance on end-of-life care for infants, children and young people with life-limiting conditions in England.¹

1. ‘End-of-life care for infants, children and young people with life-limiting conditions: Planning and management,’ National Institute for Health & Care Excellence, December 2016. [Noted in the 12 December 2016 issue of Media Watch (#491, p.12)] **Download/view at:** <https://goo.gl/8GLw37>

N.B. Access requires a subscription; March/April issue contents page: <https://goo.gl/yjWnDa>

Cont.

- *PEDIATRICS*, 2018;141(5). **'Interpretation of do not attempt resuscitation orders for children requiring anesthesia and surgery.'** Pertinent considerations for the clinician include the rights of children, decision-making by parents or legally approved representatives, the process of informed consent, and the roles of surgeon and anesthesiologist. A process of re-evaluation of the do not attempt resuscitation orders, called "required reconsideration," should be incorporated into the process of informed consent for surgery and anesthesia, distinguishing between goal-directed and procedure-directed approaches. **Full text:** <https://goo.gl/CSxXJH>

N.B. Additional articles on resuscitation protocols for pediatric patients noted in the 18 September 2017 issue of *Media Watch* (#530, p.16).

- *PEDIATRICS*, 2018;141(4). **'Changes in parental hopes for seriously ill children.'** The authors describe changes in parent hopes across multiple domains and time intervals, examine hopes in a sub-group of parents whose child died, and explore the maintenance of domains over time. One hundred and ninety-nine parents of 158 patients most often reported hopes in the domains of quality of life (75%), physical body (69%), future well-being (47%), and medical care (34%). Hope percentages increased over time for quality of life (84%), future well-being (64%), and broader meaning (21%). **Abstract:** <https://goo.gl/kTdJYX>

Media Watch 15 January 2018 (#546, p.6):

- *AMERICAN JOURNAL OF BIOETHICS*, 2018; 18(1):3-11. **'From "long shot" to "fantasy": Obligations to pediatric patients and families when last-ditch medical efforts fail.'** The authors explore the progression of care from long shot to fantasy using two pediatric cases. This progression may be differentiated into four distinct stages of care related to the potential of achieving the initial goals-of-care. Physicians are often ill prepared for the progression of treatments from a long shot hope to an unfeasible and, therefore, typically unjustified intervention. **Abstract:** <https://goo.gl/CWibZU>

Can e-learning be used to teach palliative care? Medical students' acceptance, knowledge, and self-estimation of competence in palliative care after e-learning

BMC MEDICAL EDUCATION | Online – 27 April 2018 – Undergraduate palliative care education (UPCE) was mandatorily incorporated in medical education in Germany in 2009. Implementation of the new cross-sectional examination subject of palliative care (PC), however, continues to be a major challenge for medical schools. It is clear that there is a need among students for more UPCE. On the other hand, there is a lack of teaching resources and patient availabilities for the practical lessons. Digital media and e-learning might be one solution to this problem. E-learning is a promising approach in UPCE and well-accepted by medical students. It may be able to increase students' knowledge in PC. However, it is likely that there are other approaches needed to change students' self-estimation in PC competencies. It seems plausible that experience-based learning and encounters with dying patients and their relatives are required to increase students' self-estimation in PC competencies. **Full text:** <https://goo.gl/aN9u1P>

Noted in *Media Watch* 3 October 2016 (#482, p.10):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2016;23(5):236-239. **'Online learning in palliative care: Does it improve practice.'** A literature review found no firm evidence of an improvement in patient outcomes that can be attributed to online learning. Some authors suggest that successful courses are those that combine participative and online interactive methods. The evidence base for online learning may be compromised by variables such as programme design, system requirements, degree of interactivity, educational styles and topics. There is a need for more research, but also greater conceptual clarity, and methods that can evaluate the effectiveness of training courses at design stage.

N.B. Access requires a subscription. September/October issue contents page: <https://goo.gl/nmY8MU>

Noted in *Media Watch* 26 November 2012, #281 (p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2012;2(4):292-293. **'Can e-learning be used to teach end-of-life care?'** Many clinicians and educators regard e-learning with scepticism, especially in relation to a subject as personal and sensitive as end-of-life care. This is especially the case if they have been exposed to poorly designed e-learning programmes, or those that appear irrelevant, simplistic or not rooted in the real world of practice. The increasing pressure to complete requirements for statutory and mandatory training through e-learning programmes has increased the aversion that some clinicians have toward this whole way of learning. **Abstract:** <https://goo.gl/2je3Y0>

How to explore the end-of-life preferences of homeless people in the U.K.



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(2):59-62. People experiencing homelessness receive inadequate care at the end of life (EoL), and despite homelessness being on the increase, research specifically into EoL care for this population is only now starting to be prioritised in the U.K. Indeed, no academic studies have been conducted in the U.K. to date to specifically explore what matters most to homeless people as they consider their own EoL. Their priorities are not yet known, and it should not be assumed that they will mirror those of the general population who have a home and resources and who often have multiple support networks. Creative solutions, involving flexible and adaptable professionals, are required so that appropriate and relevant palliative and EoL care services are made accessible to homeless people. However, it will not be possible to plan such services until the specific needs, preferences, priorities and concerns of our homeless population in the U.K. are better understood. Complex problems usually require multiple solutions, and it is essential to explore the problems in order to understand them deeply and be able to plan and implement solutions that this group finds acceptable and accessible.

N.B. See Abstract Watch (p.89 of this issue of the journal): 'The homeless: A vulnerable population with poor access to palliative care.' Additional articles on end-of-life care (EoLC) for the homeless in the U.K. noted in the 9 April 2018 issue of Media Watch (#558, p.4). Also, see 'A second class ending: Exploring the barriers and championing outstanding EoLC for people who are homeless,' Care Quality Commission, November 2017. [Noted in the 6 November 2017 issue of Media Watch (#537, p.5)] <https://goo.gl/5aygwT>.

Related: Perspective from The Netherlands

- *BMC PALLIATIVE CARE* | Online – 24 April 2018 – '**Palliative care for homeless people: A systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care.**' Twenty-seven publications from 23 different studies met the inclusion criteria; 15 studies were qualitative and eight were quantitative. Concerns of the homeless often related to end-of-life care not being a priority, drug dependence hindering adequate care, limited insight into their condition and little support from family and relatives. Barriers and facilitators often concerned the attitude of healthcare professionals towards homeless people. A respectful approach and respect for dignity proved to be important in good quality palliative care. **Full text:** <https://goo.gl/xcWL66>

What causes delayed discharge of end-of-life care patients who wish to die at home



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(2):68-73. The number of people with long-term conditions in England alone is projected to rise to 18 million by 2025 and these individuals will need end-of-life (EoL) care as they approach the last years, months and days of their lives. Further, the delay to discharge patients, including those at the EoL who wish to die in their own homes, costs the National Health Service about £300 million per year. In light of the aforementioned, several strategies, initiatives and policies have been put in place to improve patients' quality of care and meet their choice of preferred place of EoL care and place of death. Despite these measures, there is significant evidence that most EoL patients who wish to die in their homes still die in hospitals, and this can cause significant psychological and emotional distress among this group of

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patients and their families, friends and carers. One of the contributing factors is that staff lack the confidence, awareness and training to raise EoL issues with their patients and deliver the appropriate care. Recommendations to improve future practice include: the use of standardised early EoL assessment tools and simplified discharge paperwork; training on EoL care and the discharge process; the introduction of wider integrated services meetings with both hospital and community teams; and, the establishment of an EoL team.

Related

- *NURSING FORUM* | Online – 23 April 2018 – ‘**Ideas of home in palliative care research: A concept analysis.**’ Although identified as an important location, spatial perspectives expressed through the concept of home appear unexplored. As main results, six attributes were identified and explored: 1) Home as actor – capable of acting; 2) Emotional environment – something people have feelings for; 3) Place – a part of personal identity and a location; 4) Space – complex and relational spatial connections – a site for care; and, 5) Setting – passive background and absolute space; and, 6) Becoming – a fluid spatiality constantly folded. **Abstract:** <https://goo.gl/Jxdzkg>

Palliative care in Ireland

The dementia patient’s pathway through specialist palliative care services (Part 2)



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2018;25(2):93-95. This study highlights the need to promote a greater understanding of the role of specialist palliative care (SPC) services, particularly in the care of non-cancer patients and specifically those with dementia. Early referral to an SPC service, and improving communication between acute, residential and SPC services, can go some way to enhancing the quality of care for dementia patients and ensuring better support for those caring for them. In Ireland, many of the services for dementia patients are based around acute and residential care services. It is evident that there is a need for improvement of these services in order to support carers looking after patients with dementia in their own home. The Irish National Dementia Strategy outlines numerous recommendations, which aim to improve the lives of people with dementia across all care settings. One of its recommendations is to have better co-ordination between all primary and acute care services, including palliative care services. Its publication is a positive first step in the development of dementia care services in Ireland, but its implementation is dependent on adequate funding to resource and progress the strategy’s recommendations into the future.

N.B. Part 1 of this two-part article noted in the 26 February 2018 issue of Media Watch (#552, p.12). Additional articles on palliative care for people living with Alzheimer’s and other forms of dementia noted in the 23 April 2018 issue of Media Watch (#560, p.6).

Palliative care in humanitarian crises: A review of the literature

JOURNAL OF INTERNATIONAL HUMANITARIAN ACTION | Online – 20 April 2018 – The authors present findings from a review of the literature (2005-2017) on palliative care (PC) in humanitarian crises (e.g., disasters, armed conflicts, epidemics). This review set out to describe PC needs, practices, barriers, and recommendations in humanitarian crisis settings. It contributes to current discussions within the field of humanitarian healthcare aimed at clarifying whether or not and how best to respond to PC needs in humanitarian crises. Analysis of 95 peer-reviewed and gray literature documents reveal a scarcity of data on PC needs and interventions provided in crises, challenges of care provision particularly due to inadequate pain relief resources and guidelines, a lack of consensus on the ethics of providing or limiting PC as part of humanitarian healthcare response, and the importance of contextually appropriate care. These findings suggest more research and open discussion on PC in humanitarian crises are needed. This review contributes to defining PC needs in humanitarian crises, building consensus on humanitarian health-care organizations’ ethical responsibilities towards individuals and families with PC needs, and developing realistic and context-appropriate policies and guidelines. **Full text:** <https://goo.gl/N8cZxA>

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Related

- *PALLIATIVE MEDICINE & HOSPICE CARE* | Online – Accessed 28 April 2018 – ‘**Palliative care training for work in an austere environment after a natural disaster.**’ During a mass casualty event, healthcare responders will encounter disaster victims who are triaged to the “expectant” category of care because either their injuries are not survivable or the resources needed to care for them surpass what is available. Responders have not been traditionally trained to administer palliative care (PC) in a disaster setting. This commentary examines the challenges that responders face in caring for dying patients in the field and advocates for basic PC training prior to deploying to a disaster. **Full text:** <https://goo.gl/xskAGC>

N.B. Additional articles on the provision of palliative care during humanitarian crises or natural disasters noted in the 2 April 2018 issue of *Media Watch* (#557, p.6)].

Feasibility and acceptability of a best supportive care checklist among clinicians

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 April 2018 – Best supportive care (BSC) is often not standardized across sites, consistent with best evidence, or sufficiently described. The authors developed a consensus-based checklist to document BSC delivery, including symptom management, decision making, and care planning. They hypothesized that BSC can be feasibly documented with this checklist consistent with consolidated standards of reporting trials. The authors surveyed 15 clinicians and 9 advanced practice providers. Represented specialties were medical oncology, gynecologic oncology and palliative care (PC). For “overall impact on your delivery of supportive/PC,” 40% [in this study] noted improved impact with using BSC. For “overall impact on your documentation of supportive/PC,” 46% noted improvement. Impact on “frequency of comprehensive symptom assessment” was noted to be “increased” by 33% of providers. None noted decreased frequency or worsening impact on any measure with use of BSC. Regarding feasibility of integrating the checklist into workflow, 73% agreed/strongly agreed that checklists could be easily integrated, 73% saw value in integration, and 80% found it easy to use. **Abstract:** <https://goo.gl/kSWDxY>

Patients prefer doctors who engage in face-to-face visits

MEDICAL PRESS | Online – 24 April 2018 – Patients prefer physicians who engage in face-to-face (F2F) clinic visits, rather than those using an examination room computer (ERC), according to a {recent} research letter...¹ Ali Haider MD, from the University of Texas MD Anderson Cancer Center in Houston, and colleagues conducted a randomized controlled crossover study involving 120 patients from a palliative care clinic. Patients’ perceptions of physicians’ compassion were assessed after watching two standardized scripted-video vignettes of physicians: one portraying F2F clinic visits and one portraying a physician using an ERC. The researchers found that after watching and assessing the first video, the F2F visit resulted in better scores for compassion, communication skills, and professionalism. “Proper optimization of the ERC and clinicians’ training might improve patients’ perception,” the authors write. “Because current health care delivery necessitates the use of electronic health records, future studies focusing on strategies that can mitigate the negative effects of the ERC use on physician-patient communication are imperative.” **Overview:** <https://goo.gl/5whVr1>

1. ‘Physicians’ compassion, communication skills, and professionalism with and without physicians’ use of an examination room computer: A randomized clinical trial,’ *JAMA Oncology*, published online 19 April 2018. **First page preview:** <https://goo.gl/LCqnSK>

The palliative care questions to ask every advanced breast cancer patient

MEDSCAPE | Online – 25 April 2018 – Despite the proven benefits of early palliative care (PC) for oncology patients, integration of PC remains a challenge. At Johns Hopkins Medicine, the TEAM (Time, Education, Assessment, and Management) approach is being used to improve oncology outcomes by incorporating PC in practice for patients with advanced breast cancer. TEAM requires approximately one hour

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of additional time with the patient each month, focused on patient education, assessment, and management. "It is an extra hour every month, not once. [But] it doesn't have to be done by the doctor. It can be an advanced practice or [other trained] nurse," said Thomas Smith, MD, director of palliative medicine and professor of oncology at Johns Hopkins. The hour can be spent in person, by phone, or by telemedicine, but it has to be structured and include assessments, he added. The benefits of early PC have been firmly established. In 6 of 13 large randomized trials, early outpatient PC has been shown to improve survival, and no trials have identified any harms. Early PC also decreases costs, with one recent study showing that a new PC program at Johns Hopkins saved roughly \$3.5 million on health system finances over one year. Of note, said Smith, other studies have shown that patients who use hospice live a month longer than patients who don't use hospice. [12,13] Full text: <https://goo.gl/RQRSuo>

Noted in Media Watch 6 November 2017 (#537, p.7):

- *BREAST CANCER RESEARCH & TREATMENT* | Online – 30 October 2017 – ‘**The value of embedding: Integrated palliative care for patients with metastatic breast cancer.**’ Recent data show benefits of early PC (at least 90 days before death). However, little is known about PC among patients who die from metastatic breast cancer. In the 18-month study period, oncologists referred for PC 105 of their 515 (20.4%) patients; 59 (11.5%) patients were seen by the PC physician. Of the 38 referred patients who died, 23 (60.5%) were seen by embedded PC and all 23 received PC within 90 days of death. **Abstract (inc. list of references):** <https://goo.gl/TVuk7L>

End-of-life care in The Netherlands

Living longer than expected: Admitted to a hospice with an underestimated life expectancy

NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE | Online – accessed 25 April 2018 – In The Netherlands, patients who have a life expectancy of less than three months may be admitted to a hospice. In a small number of patients, however, their life expectancy is underestimated. It is assumed that patients are delighted to have this extra time. The authors present the cases of three patients admitted to a large Dutch hospice: two females aged 82 and 83 years, and a 49-year-old man – who ended up living (significantly) longer than expected. Their cases make clear that patients in this situation may suffer from psychological, psychosocial, and existential distress. The authors argue that it is important that patients and their relatives are informed about their life expectancy, but that uncertainty in the estimation of said expectancy should be emphasized. **Abstract:** <https://goo.gl/vf8yzc>

N.B. Dutch language article.

End-of-life care in Norway

Nurses' experience with relatives of patients receiving end-of-life care in nursing homes and at home: A questionnaire-based cross-sectional study

NURSING OPEN | Online – 19 April 2018 – The Norwegian healthcare system is based on the Scandinavian public welfare model and mainly financed by the income tax system. Health care is a legislative right for all, whether specialized care in hospitals or long-term care (LTC) in nursing homes or at home. Specialized care is financed and regionally organized by central state health authorities. Primary health care, including LTC, is financed and organized by the municipalities. There are some major differences in the organization of end-of-life care (EoLC) between nursing homes and home-based care. Among other things, the clinical experience of healthcare personnel over time makes a difference and that collegial support at nursing homes is much stronger than in home-based care setting, where nurses more often operate alone. Contemporary palliative care in Norway includes a wide spectrum of diseases, in addition to a focus on oncology. Due to this, nurses dealing with EoLC in nursing homes and in home-based care face an increasing challenge. **Full text:** <https://goo.gl/J5tmns>

N.B. English language article.

Mobile health technology and home hospice care: Promise and pitfalls

PROGRESS IN PALLIATIVE CARE | Online – 26 April 2018 – With the increasing use of mobile devices (e.g., smart phones, tablets) in our everyday lives, people have the ability to communicate and share information faster than ever before. This has led to the development of promising applications aimed at improving health and healthcare delivery for those with limited access. Hospice care, which is commonly provided at home, may particularly benefit from the use of this technology platform. This commentary outlines several potential benefits and pitfalls of incorporating mobile health applications into existing home hospice care while highlighting some of the relevant telemedicine work being done in the palliative and end-of-life care fields. **Abstract:** <https://goo.gl/PRaDSa>

Noted in Media Watch 26 June 2017 (#518, p.6):

- *BMC MEDICINE* | Online – 19 June 2017 – ‘**The effect of weekly specialist palliative care teleconsultations in patients with advanced cancer: A randomized clinical trial.**’ Despite promising earlier research, the present study shows that telemedicine does not necessarily lead to a better quality of advanced cancer care. Indeed, the use of telemedicine might create a situation in which patients experience a higher symptom burden, despite high degrees of satisfaction. **Full text:** <https://goo.gl/AFPhXp>

N.B. Additional articles on the pros and cons of telehealth/telemedicine in the context of palliative and end-of-life care noted in the 13 March 2017 issue of Media Watch (#503, p.12).

Spiritual care: Literature review

SPIRITUAL CARE | Online – 24 April 2018 – This literature review presents the spiritual needs described by nursing home residents, the providers of spiritual care (SC), characteristics of residents receiving SC, and the kind of interventions understood as SC. Moreover, it summarizes how SC was measured in long-term care so far. Four challenges for nursing care and research are derived from the results: 1) While SC will always be offered in an individual and context-specific way, its further development needs a clear conceptual framework which can guide both, practice and research; 2) The “spiritual” part of SC needs to be filled with content, preferably within an interprofessional context; 3) SC is in danger of being mixed with other nursing concepts such as person-centred or psychosocial care (a clear distinction is needed for it to support a holistic approach in nursing care); and, 4) While there are basic criteria to measure structures and processes of SC, some effort is needed to lay the groundwork for measuring SC outcomes. **Abstract (inc. list of references):** <https://goo.gl/26HjjW>

N.B. German language article. Additional articles on spirituality in the context of end-of-life care noted in the 23 February 2018 issue of Media Watch (#560, p.17).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *AMERICAN JOURNAL OF NURSING*, 2018;118(5):50-59. ‘**Assisted suicide/aid in dying: What is the nurse’s role?**’ This article presents the discussion that occurred during a policy dialogue on aid in dying (AiD) presented at the American Academy of Nursing’s annual conference in October 2016. Panelists explored the arguments for and against the growing state expansion of AiD legislation, and the role for nurses in assisting patients who request AiD. Recommendations are offered and four expert commentaries respond to the points raised. **Summary:** <https://goo.gl/iM5WTX>
- *EUROPEAN JOURNAL OF EPIDEMIOLOGY* | Online – 21 April 2018 – ‘**How accurately is euthanasia reported on death certificates in a country with legal euthanasia: A population-based study.**’ [In Belgium) death certificates are the main source of information on the incidence of the direct and underlying causes of death, but may be unsuitable for monitoring the practice of medical assistance in dying, e.g., euthanasia, due to possible underreporting. Euthanasia was more likely to be reported on the death certificate where death was from cancer (14% covered), neurological diseases (22%) and stroke (28%) than from cardiovascular disease (7%). Even when the recommended drugs were used or the physician self-labelled the end-of-life decision as euthanasia, euthanasia was only reported on the death certificate in 24% of cases. **Abstract (inc. a list of references):** <https://goo.gl/B3mEzU>

Journal Watch

Opportunistic journals in the clinical pharmacology space: A policy statement from the Publications & Public Policy Committees of the American College of Clinical Pharmacology

CLINICAL PHARMACOLOGY IN DRUG DEVELOPMENT | Online – 20 April 2018 – “Predatory journal” is the customary term, but “opportunistic journal” is more accurate. The situation that we face is a product of economic opportunity in a free-market economy. Profit is to be made through business enterprises founded to fill a need for a product or service that people are willing to pay for. In addition, an awards system has been put in place by some foreign governments based only on having a publication in a journal. Entrepreneurs of predatory journals have stepped forward to fill these “needs,” apparently with substantial success. The problem is that the legitimate biomedical publication process, and the system of merit-based peer-review used by academic medical and scientific journals, are collateral damage. **First page preview:** <https://goo.gl/ZHM8hy>

Cabells’ journal whitelist and blacklist: Intelligent data for informed journal evaluations

LEARNED PUBLISHING | Online – 19 April 2018 – Cabells’ whitelist of 11,000 quality journals has recently been joined by a blacklist of over 8,300 journals that fail basic quality criteria. Cabells’ journal blacklist is the only searchable database of deceptive and fraudulent journals with comprehensive reports detailing violations. Key components for establishing the blacklist were objectivity and transparency with respect to the evaluation process and selection criteria, and unbiased evaluations. The blacklist evaluation criteria were tested to ensure accurate judgement and are continually evolving to maintain suitability. Over 800 journals are added to the blacklist each month. **Abstract:** <https://goo.gl/qjoWFh>

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Updated 04.27.2018

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INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/T2tCWF>

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ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <https://goo.gl/ZRngsv>

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[Scroll down to ‘International Websites’]

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BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: <https://goo.gl/qw5ti8>

[Click on ‘National Resources,’ scroll down to ‘Palliative Care Network Community’]

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CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <https://goo.gl/BLgxy2>

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EUROPEAN JOURNAL OF PALLIATIVE CARE: <https://goo.gl/KjrR6F>

[March/April 2018 issue (Scroll down to 'The homeless: A vulnerable population with poor access to palliative care.')]

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/3jnH7K>

U.K. | Omega, the National Association for End-of-Life Care: <http://goo.gl/UfSZtu>

South America



Academia Nacional de Cuidados Paliativos (Brazil): <https://goo.gl/b5CV31>

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