

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.

28 January 2019 Edition | Issue #599



Compilation of Media Watch 2008-2019 ©

Compiled & Annotated by Barry R. Ashpole

‘Correlates of perceived death competence: What role does meaning-in-life and quality-of-life play?’ (p.14), in *Palliative & Supportive Care*.

Canada

Care and compassion: Champlain Local Health Integration Network looks to modernize home care

ONTARIO | *The Ottawa Citizen* – 23 January 2019 – There are more than 20,000 patients on the home care roster of the Champlain Local Health Integration Network (LHIN). More than 60,000 people in the region receive home care over the course of a year at a cost of \$250 million. If these patients were to be cared for in hospital or long-term care homes, it would cost the system \$170 million more. The LHIN has some staff to manage and deliver home care. But most services are delivered by contractors and community service organizations that receive funding through the LHIN. Demand for home care is increasing at the rate of about 3% a year. By 2038, there will be more than 117,000 home care patients annually. The LHIN acknowledges that the shortage of personal support workers (PSWs) is one of the biggest home care challenges but believes that an equally great or greater underlying problem may be how PSWs are organized and deployed by contrac-

tors – it’s a productivity problem, not a workforce size problem. Family caregivers also play a major role in the home care system. The strategic plan will look at the implications if this support system declines, especially as the population ages. Developing a strategic plan for home care is one of the key initiatives for the LHIN. The LHIN aims to move away from the “fragmented” rehabilitation model – based on short-term goals that don’t do much to allow the patient to live independently – to the “targeted” model aimed at making patients more independent, which also drives down costs. <https://goo.gl/YwfQrC>

Specialist Publications

‘An analysis of documents guiding palliative care in five Canadian provinces’ (p.8), in *Canadian Journal on Aging*.

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Noted in Media Watch 14 January 2019 (#597, p.7):

- **BMC PALLIATIVE CARE** | Online – 9 January 2019 – ‘**Potential quality indicators for seriously ill home care clients: A cross-sectional analysis using Resident Assessment for Home Care data in Ontario.**’ In Ontario, several initiatives are underway to improve the quality of palliative care services across the province. For example, Health Quality Ontario and the Ontario Palliative Care Network are developing quality standards and indicators for palliative services.^{1,2} The preliminary list of quality indicators proposed here can make a significant contribution to this process as these organizations work collaboratively with home care providers and researchers to establish a set of standardized measures. **Full text:** <https://goo.gl/F8v1ij>
 1. ‘Care for Adults With a Progressive, Life-Limiting Illness,’ (Quality Statements in Brief), Health Quality Ontario. **Download/view at:** <https://goo.gl/gYHTBW>
 2. Ontario Palliative Care Network (Action Plan). **Download/view at:** <https://goo.gl/iVzci9>

N.B. See ‘Palliative Care at the End of Life,’ Health Quality Ontario, June 2016. [Noted in 4 July 2016 issue of Media Watch (#469, p.2)]; selected articles on palliative care in the province also noted in this issue of the weekly report.] **Download/view at:** <https://goo.gl/jTW7qa>

[U.S.A.](#)

[When cancer meets the Internet](#)

Dr. Google doesn’t always know what’s best

THE NEW YORK TIMES | Online – 21 January 2019 – When faced with an actual or potential diagnosis of cancer, most people are inclined to consult Dr. Google, often before they see a real live medical expert. Unfortunately, Dr. Google doesn’t always know what’s best. A generation ago, patients were largely dependent upon the physicians they consulted as to how best to deal with a disease like cancer. Nowadays there’s the Internet, replete with a virtual tsunami of information offered by all kinds of sources, from experts equipped with evidence-based facts to people selling products or outright quackery. The trick is to know how to tell the difference, especially since the disparate guidance provided can become a matter of life or death. In a review of 170 studies of patients who use information technology, Danielle Gentile of the Levine Cancer Institute of Atrium Health ... and her co-authors found that social media communities can be very helpful to cancer patients, especially those who lack personal social support.¹ Cancer patients can converse with others, anonymously or otherwise, about emotional and spiritual issues and glean helpful firsthand tips on dealing with treatment-related issues. But while some online communities “are curated by medical professionals, others may be posted by people who

have no scientific knowledge,” Dr. Schapira cautioned. The information patients glean through such lay communities is best discussed with their doctors lest they be led down the garden path of bad advice. She also suggested that patients not be pressured to research their cancers until and unless they are emotionally and intellectually ready to deal with the information they uncover. <https://goo.gl/XjktFJ>

Palliative care content on cancer center websites

SUPPORTIVE CARE IN CANCER | Online – 9 October 2017 – The authors conducted a content analysis of 62 National Cancer Institute designated cancer center websites. 10% had no webpage with palliative care (PC) information for patients. Among centers with information for patients, the majority (96%) defined palliative or supportive care, but 30% did not discuss delivery of PC alongside curative treatment, and 14% did not mention provision of care early in the disease process. **Abstract (inc. list of references):** <https://goo.gl/6vEYhL>

N.B. This article was noted in 16 October 2017 issue of Media Watch (#534, p.16).

1. ‘Patients with cancer and social media: Harness benefits, avoid drawbacks,’ *Journal of Oncology Practice*, 2018;14(12):731-736. **Abstract:** <https://goo.gl/QDnT3u>

Advance-directive wishes aren't always lock-tight

NEW HAMPSHIRE | *New Hampshire Union Leader* (Manchester) – 19 January 2019 – Ann Franz medically-prolonged life while battling profound dementia, late-stage chronic obstructive pulmonary disease and recurrent pneumonia – and her daughters' grief over wishes not honored – is a cautionary tale about the gray areas, legal requirements and limitations of defining quality and duration of life. In quarterly on-site meetings with nursing home staff and administrators, and updates by phone when Franz's condition was changing, "We went over her wishes so they would understand," said Franza Giffen, her daughter in San Francisco who serves as a fiduciary for elders in California and is familiar with the law. "They took care of her the way they wanted to and felt was right instead of following the letter of her wishes." Such is the Achilles heel of advance directives – the documents designed to protect end-of-life desires. Even when one's intent is made clear, and there are representatives to carry that out, on-site interpretation by medical staff who feel ethically bound to preserve life can color the interpretation – and extend life even when quality has long departed. And sometimes, in the final hours, patients plea for emergency assistance – which effectively trumps the papers they signed years ago declining heroic life-saving treatment... <https://goo.gl/YVrM6f>

N.B. Selected articles on advance directives in the U.S. health care system noted in 21 January 2019 issue of Media Watch (#598, pp.8-9).

International

Pain's east-west divide

POLITICO | Online – 24 January 2019 – In the European Union, residents of Western Europe are far more likely to receive what's known as palliative care (PC) than those living in the East. Indeed, the line separating countries that routinely offer pain relief and emotional support to cancer patients from those that expect them to tough it out cleaves the Continent in two. The availability of the pain-killing opioid is, generally speaking, a good marker for the availability of PC. A 2010 study conducted by the European Society for Medical Oncology and the European Association for Palliative Care found "profound differences" between East and West. The top nine countries for morphine usage were all in Western Europe, the lowest nine were all in Eastern Europe. Before the PC movement got going in the 1960s, there was not much difference in morphine consumption. But by 2006, average morphine consumption per person in Western Europe was about 12 times what it was in Eastern Europe. <https://goo.gl/corFUy>

Specialist Publications

'How to conserve dignity in palliative care: Suggestions from older patients, significant others, and healthcare professionals in Swedish municipal care' (p.7), in *BMC Palliative Care*.

'Experts' views on palliative care provision for patients with migration background in Germany' (p.7), in *BMC Palliative Care*.

'Palliative care: A future challenge for the Cuban health system' (p.9), in *International Journal of Cuban Studies*.

'Hospice and palliative care volunteering in The Netherlands: Practices of "being there"' (p.14), in *Palliative Medicine in Practice*.

'Social representation of palliative care in the Spanish printed media: A qualitative analysis' (p.16), in *Plos One*.

Noted in Media Watch 16 April 2018 (#559, 10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 April 2018 – **'Access to strong opioid analgesics in the context of legal and regulatory barriers in eleven Central and Eastern European countries.'** In 2011-2013, 95% of the global opioid analgesics consumption occurred in three regions, accounting for 15% of the world population. Despite abundant literature on barriers to access, little is known on the correlation between actual access to opioid analgesics and barriers to access, including legal and regulatory barriers. In this study, no correlation was found, which indicates that other factors besides potential legal and regulatory barriers play a critical role in withholding prescribers and patients essential pain medication in the studied countries. **Abstract:** <https://goo.gl/urBsHg>

Amendment to Act on the Medical Profession

AUSTRIA | *International Law Office* – 23 January 2019 – Due to demographic changes in recent years, there have been ongoing debates about end-of-life care, questions associated with human dignity, and corresponding developments in medical treatment. In the new Section 49a of the Act on the Medicinal Profession – which is similar in style to the German template for professional rules – the scope of the obligation for physicians to provide medical assistance for dying patients is formally laid out in law. Section 49a(1) provides that a physician must assist dying patients to preserve their dignity. Section 49a(2) specifically provides that within the scope of quality-assured palliative indications, all measures must be taken to relieve pain and torment despite the risk that this may accelerate the loss of vital functions. This amendment clarifies that pain relief takes precedence over the prolongation of life, but this does not permit active euthanasia, which remains prohibited in Austria. <https://goo.gl/R1cQCF>

Change cruel law to help the dying: Scandal of terminally ill denied benefits

U.K. (England, Northern Ireland & Wales) | *The Daily Express* (London) – 23 January 2019 – Charity Marie Curie said according to government figures, thousands of terminally ill patients were among the 17,000 who died awaiting decisions from 2013-2018. People can get fast-track access to tax-free Personal Independence Payments (PIP) at the highest rate if a doctor or nurse says they have less than six months to live. But Marie Curie says those with unpredictable illnesses like lung and motor neurone disease cannot always meet this criteria and face being left without support. Some are even forced to attend back-to-work interviews to continue receiving financial help. Marie Curie and the Motor Neurone Disease Association are urging the government to scrap the cruel six-month limit... Britons can claim up to £145 PIP a week if they are aged 16 to 64, their health condition or dis-

ability makes day-to-day life difficult, and can be reasonably expected to die within six months. Department for Work & Pensions figures show 95% of people accessing benefits via the six-month rule have terminal cancer – meaning those with unpredictable terminal illnesses often miss out. The charities want doctors to be free to use their judgment of whether a person is terminally ill without being subject to an arbitrary time limit. <https://goo.gl/Qrgmbv>

Specialist Publications

'Palliative care in motor neurone disease: Where are we now?' (p.13), in *Palliative Care: Research & Treatment*.

Noted in Media Watch 26 November 2018 (#591, p.4):

- U.K. (Northern Ireland) | BBC News (Belfast) – 21 November 2018 – **'Personal Independence Payments: Department "cannot" scrap terminal illness form.'** In June, a review recommended the form for Personal Independence Payments (PIP) be removed. The Department for Communities said it cannot implement this recommendation. More than 100,000 people in Northern Ireland are being reassessed for PIP, which replaces the Disability Living Allowance. The review ... recommended that the clinical judgement of a medical practitioner indicating that the claimant has a terminal illness should be sufficient to secure the benefit payments. <https://goo.gl/47k5no>



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>

End “inequality” of terminally ill dementia patients paying for their care, says report

U.K. (Scotland) | *The Herald* (Glasgow) – 22 January 2019 – Elderly Scots crippled by advanced dementia are paying an estimated £50.9 million a year for care that fails to meet their needs because the condition is not treated “as an illness,” a landmark report has warned.¹ An expert group, chaired by former First Minister Henry McLeish, warned that sufferers and their families were being let down by a system that brackets advanced dementia as a social care – not a healthcare – problem. The latest figures show that dementia is now the leading cause of death among women in Scotland, and prevalence is set to rocket as the population ages. However, the report ... said people with advanced dementia “do not have equality of access to healthcare” on a par with other progressive terminal illnesses, and are “dispropor-

tionately subject to social care charges.” The report calls on the Scottish Government to commit to investigating the costs of providing “appropriate and free health care” to people living with and dying from advanced dementia in Scotland. <https://goo.gl/95amWZ>

Specialist Publications

‘Dementia and Parkinson’s disease: Similar and divergent challenges in providing palliative care’ (p.8), in *Frontiers in Neurology*.

‘The effect of a comprehensive dementia care management program on end-of-life care’ (p.9), in *Journal of the American Geriatrics Society*

1. ‘Delivering Fair Dementia Care For People With Advanced Dementia,’ Fair Dementia Care Commission, Alzheimer’s Scotland, January 2018. **Download/view at:** <https://goo.gl/KhDqJp>

St. Clare’s Hospice closes after more than 30 years

U.K. (England) | *The Shields Gazette* (South Shields) – 21 January 2019 – St. Clare’s Hospice has announced it has closed after entering into insolvent liquidation. The Jarrow-based hospice has been providing specialist care and support to adults living with life-limiting illnesses and their families in South Tyneside since it opened in 1987. But now the independent hospice has announced it has closed following a decision to enter into insolvent liquidation. The charitable trust which runs the hospice has faced severe financial difficulties for a number of years, which has been compounded by a prolonged period of closure last year, leaving it insolvent. The hospice has annual operating costs of £2.2 million and usually raises £1.8 million each year through voluntary giving, with the balance coming from the contracts with the South Tyneside Clinical Commissioning Group. The closure of the hospice’s in-patient and day services for four months last year severely restricted fundraising. <https://goo.gl/LZb8VY>

Noted in Media Watch 15 October 2018 (#585, p.7):

- U.K. (England) | *The Guardian* (London) – 8 October 2018 – ‘Hospices care for 200,000 people a year, but they’re powered by voluntary effort.’ On average, hospices receive only a third of their funding from the state; children’s hospices get even less. And for most, that contribution has been shrinking. In 2016-2017, two in three hospices in England reported that their state funding, which comes typically from local National Health Service commissioners, had been frozen or cut. Almost 80% said they had been forced to rely more on charitable giving, and more than half had dipped into reserves. <https://goo.gl/AnkCfU>



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 p.18.

Specialist Publications

“Just too busy living in the moment and surviving”: Barriers to accessing health care for structurally vulnerable populations at end-of-life

BMC PALLIATIVE CARE | Online – 26 January 2018 – Despite access to quality care at the end-of-life (EoL) being considered a human right, it is not equitable, with many facing significant barriers. Most research examines access to EoL care for homogenous “normative” populations, and as a result, the experiences of those with differing social positioning remain unheard. For example, populations experiencing structural vulnerability, who are situated along the lower rungs of social hierarchies of power (e.g., poor, homeless) will have unique EoL care needs and face unique barriers when accessing care. However, little research examines these barriers for people experiencing life-limiting illnesses and structural vulnerabilities. The authors identified five significant barriers to accessing care at EoL were identified: 1) The survival imperative; 2) The normalization of dying; 3) The problem of identification; 4) Professional risk and safety management; and, 5) The cracks of a “silo-ed” care system. Together, findings unveil inequities in accessing care at EoL and emphasize how those who do not fit the “normative” palliative-patient population type, for whom palliative care programs and policies are currently built, face significant access barriers. Findings of this study contribute a nuanced understanding of the needs of and barriers experienced by those who are both structurally vulnerable and facing a life-limiting illness. Such insights make visible gaps in service provision and provide information for service providers, and policy decision-makers alike, on ways to enhance the equitable provision of EoL care for all populations. **Full Text:** <https://goo.gl/f8WKwb>

Memory-making in end-of-life care in the adult intensive care unit: A scoping review of the research literature

AUSTRALIAN CRITICAL CARE | Online – 17 January 2019 – Four activities facilitating memory making as part of end-of-life care for adults are reported in the literature, all in the intensive care setting. Use of a computer-generated word cloud image received by families in the intensive care was reported as a meaningful keepsake and sometimes displayed in places such as the patient’s funeral memorial. Offering a printed copy of the patient’s electrocardiogram as a memento was considered by some to be extremely or very helpful during their bereavement experience and was reported by nursing staff to be well received by family members. The use of patient diaries during bereavement has been reported with the potential to promote better understanding of the events leading to the death, and photography was also included in some patient diaries as a visual memento. Although limited evidence is available concerning memory making in the adult intensive care environment, from studies to date, surviving family members of deceased patients in the intensive care unit mostly report valuing memory-making opportunities when offered. However, further research is required to evaluate both healthcare staff’s competence and confidence in offering memory making and determine if such offerings promote the family’s adjustment to the loss of their loved one after a death in the intensive care area. **Abstract (inc. link to references):** <https://goo.gl/9qoxAg>

Caregiver exposure to critical events and distress in home-based palliative care in Germany: A cross-sectional study using the Stressful Caregiving Adult Reactions to Experiences of Dying scale

BMC PALLIATIVE CARE | Online – 24 January 2019 – The findings of this study suggest that the family caregivers with home-based palliative care in Germany are facing a number of critical health events of the dying patients, resulting in fear and helplessness; both exposure and distress are associated with poor health. In addition to the initial study in hospice settings from the U.S., the authors found that the Stressful Caregiving Adult Reactions to Experiences of Dying (SCARED) scale could be applied as a screening tool in home-based palliative care setting to identify distressed family caregivers with a potential need of extra or further support. Considering the negative effects of caring for a dying relative on individuals, families, and societies, future research, with a well-tested instrument in the palliative practice assessing caregivers’ psychosocial situation, such as the SCARED scale, is recommended or suggested within and beyond American and German contexts. **Full text:** <https://goo.gl/ECXJ8k>

How to conserve dignity in palliative care: Suggestions from older patients, significant others, and healthcare professionals in Swedish municipal care

BMC PALLIATIVE CARE | Online – 24 January 2019 – This study confirms dignity conserving care is not just what is done for the patient, but also how the patient is viewed. This can be operationalised through specific and concrete care actions, as well as all-embracing attitudes and behaviours that conserve the patient's dignity. In adapting the Dignity Care Intervention (DCI) to a Swedish context, the authors took into consideration the perspectives of older persons with palliative care (PC) needs, their significant others, nurses and physicians. Relevant care actions were added to the original ones in the Scottish DCI. The DCI-SWE can be used by nurses to care for patients with PC needs in general care. It has the potential to facilitate the nurses' knowledge and to ensure evidence-based quality in palliative care. The effectiveness of the intervention and responses to it will be further researched. **Full text:** <https://goo.gl/FStFKz>

“An odyssey without receiving proper care.”

Experts' views on palliative care provision for patients with migration background in Germany

BMC PALLIATIVE CARE | Online – 21 January 2019 – Though needs and wishes of migrant patients are found to often be similar to those of non-migrant patients, there are migration-specific aspects that can influence care provision at the end of life (EoL). Migration should be regarded as a biographical experience that has a severe and ongoing impact on the life of an individual and their family. Legal aspects concerning migration status can influence access to and provision of care. Language barriers have to be considered, especially regarding patients' right to informed decision making. In 2008, Babitsch *et al* stated that to ensure culturally sensitive and competent health care, institutions have to consider and accept cultural diversity, and provide access to professional medical interpreters.¹ They also conclude that most German hospitals don't fulfil these requirements, and it seems that little has changed in the last ten years. The reimbursement of interpreters in health care remains an open question. The use of professional medical interpreters, and intercultural awareness training for health professionals are widely recommended measures to ensure adequate health care for all patient groups, and institutions providing hospice and palliative care are no exception. Further research should focus on patient's perspectives to deepen the understanding of their needs, and on care pathways for migrant patients to identify access barriers to appropriate EoL care. **Full text:** <https://goo.gl/MxA4PY>

1. 'Doctor's perception of doctor-patient relationships in emergency departments: What roles do gender and ethnicity play?' *BMC Health Services Research*, first published online 11 April 2008. **Full text:** <https://goo.gl/oJC4gz>

N.B. Additional articles on palliative and EoL care for immigrants in Germany noted in 8 October 2018 issue of *Media Watch* (#584, p.11).

End-of-life care in Belgium

Impact of palliative home care support on the quality and costs of care at the end of life: A population-level matched cohort study

BMJ OPEN | Online – 21 January 2019 – The findings from this nationwide retrospective matched cohort study show the positive impact of palliative home care (PHC) support on the quality of end-of-life (EoL) care. Additionally, the authors found that while the total costs for home care is higher, the average total reimbursed costs of medical care at the EoL is significantly lower for those who used PHC support. Their findings based on complete population national data add important scientific evidence of the positive impacts PHC support has on the appropriateness of EoL care and on reducing societal costs related to care at the EoL. Because PHC support appears widely underused, the results of this study suggest that increasing its availability and stimulating its use, therefore, has a potential to improve the appropriateness of care at the EoL of patients and at the same time reduce the expenses for the health insurer. **Full text:** <https://goo.gl/tUo9ai>

An analysis of documents guiding palliative care in five Canadian provinces

CANADIAN JOURNAL ON AGING | Online – 24 January 2019 – The purpose of this study was to analyse the consistency and extent of palliative content across high-level guiding documents related to the care of persons residing in Canadian long-term care (LTC) homes. A systematic search was conducted examining documents at the national level and across five provinces (Alberta, Ontario, Saskatchewan, Manitoba, and Quebec). Twenty-five documents were selected based on inclusion criteria from 273 documents identified in the systematic search. The majority of these documents were created nationally (48%) or in Ontario (28%). Documents varied in palliative topics discussed, and LTC was discussed minimally. A minimal number of palliative care guiding documents were found. LTC specific documents were absent, and all documents lacked consistency on palliative topics. It is imperative that palliative principles are present and consistent in high-level documents in order to improve the quality of life and care for LTC residents across Canada. **Abstract (w. list of references):** <https://goo.gl/4fJXiJ>

Noted in Media Watch 21 January 2019 (#598, p.5):

- *AGEING & SOCIETY* | Online – 15 January 2019 – ‘**Mind the gap: Is the Canadian long-term care workforce ready for a palliative care mandate?**’ As little is known about the readiness of long-term care LTC staff in Canada to embrace a palliative care (PC) mandate, the main objective of this study was to assess qualities relevant to PC, including personal emotional wellbeing, PC self-efficacy and person-centred practices... The results of this study suggest that the emotional wellbeing of the Canadian LTC workforce is unlikely to impede effective PC. However, PC self-efficacy and person-centred care can be further cultivated in this context. **Abstract (w. list of references):** <https://goo.gl/6xe2DE>

Noted in Media Watch 14 January 2019 (#597, p.7):

- *CANADIAN JOURNAL ON AGING*, 2019;11(1):1-13. “‘**That just breaks my heart**’”: **Moral concerns of direct care workers providing palliative care in long term care homes.**’ The literature on ethics in healthcare that explores the moral concerns of care providers typically focuses on registered health professionals and ethical dilemmas in acute and primary care. Far less attention has been paid to the long-term care environment and non-registered, direct care workers. In this research, two main moral dilemmas were ensuring that residents don’t die alone, and providing the appropriate care based on residents’ wishes. **Abstract (via PubMed):** <https://goo.gl/41Ggzi>

Dementia and Parkinson’s disease: Similar and divergent challenges in providing palliative care

FRONTIERS IN NEUROLOGY | Online – 16 January 2019 – To inspire future service development and research, the authors compare the trajectories and conceptualization of palliative care (PC) between dementia and Parkinson’s disease. Both are characterized by a protracted course, with progressive but fairly insidious development of disability. However, patients with Parkinson’s disease may experience relatively stable periods initially, but with time a wide range of debilitating symptoms develops, many of which do not respond well to treatment. Eventually, dementia develops in most Parkinson patients, while motor disability develops in many dementia patients. Advance care planning has benefits in terms of being prepared before the disease progresses into a stage with communication problems or severe cognitive impairment. However, for both conditions, the protracted disease trajectories complicate conceptualization of PC through different stages of the disease, with pertinent questions such as when to offer what interventions pro-actively. Given the similarities and differences, we should develop palliative approaches that are partially generic and partially disease-specific. These should be integrated seamlessly with disease-specific care. Substantial research is already being performed on dementia PC. This may also inform the further development of PC for Parkinson’s disease, including an evaluation of palliative interventions and services. **Abstract:** <https://goo.gl/hPZzyx>

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Closing the Gap Between Knowledge & Technology
<http://goo.gl/OTpc8l>

Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 24 January 2019 – ‘**The effect of a comprehensive dementia care management program on end-of-life care.**’ Although Alzheimer disease and other dementias are life limiting, only a minority of these patients or their proxy decision makers participate in advance care planning (ACP). The authors describe end-of-life (EoL) care preferences and acute care and hospice use in the last 6 months of life for persons enrolled in a comprehensive dementia care management program. Enrollees in a comprehensive dementia care co-management program had high engagement in ACP, high rates of hospice use, and low acute care utilization near the EoL. Wider implementation of such programs may improve EoL care for persons with dementia. **Abstract:** <https://goo.gl/N48bhR>

N.B. Selected articles, reports, etc., on palliative and end-of-life care (P&EoLC) for people living with Alzheimer’s and other forms of dementia noted in several past issues of Media Watch, for example: 7 January 2019 (#596, pp.9-10); and, 10 and 31 December 2018 (respectively, #593, p.7 and #595, p.16). Selected articles on the P&EoLC for patients living with Parkinson’s disease noted in 1 October 2018 (#583, p.13).

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

Essentials of hospice: What every practitioner needs to know but are afraid to ask

INTERNAL MEDICINE REVIEW, 2019;5(1). Every practitioner, regardless of specialty and setting of patient care, must advocate for and facilitate timely patient access to comprehensive palliative and hospice care as patients enter the last phase of life due to advanced serious life-limiting illness. Accordingly, practitioners need to be familiar with both the general and disease-specific eligibility guidelines for hospice, the four different levels of hospice care under the Medicare Hospice Benefit, reimbursement for services provided, and be proficient and culturally competent in advance health care planning as well as acquire expertise in the treatment of pain and non-pain symptoms that occur at end-of-life. This is critical to alleviate both patient and family suffering and to ensure dignity and a peaceful death. **Abstract (w. list of references):** <https://goo.gl/fjtZkt>

Palliative care: A future challenge for the Cuban health system

INTERNATIONAL JOURNAL OF CUBAN STUDIES, 2018;10(2):230-237. Nineteen percent of Cuba’s population is aged 60 years or older, with a death rate of 712.4 deaths per 100,000 inhabitants, and where malignant tumors already occupy the first cause of mortality. The authors argue that despite having a public health system that covers 100% of the population and recognition by administrative structures and decisions-makers of the need to plan strategies to face these challenges, these efforts are insufficient. The development of palliative care in Cuba is not only a new challenge, but also a moral and material need, inherent to truly social medicine. **First page view:** <https://goo.gl/YGcZUs>

Teaching nurses to teach: A qualitative study of nurses’ perceptions of the impact of education and skills training to prepare them to teach end-of-life care

JOURNAL OF CLINICAL NURSING | Online – 22 January 2019 – Central to national and international policies is the need for generalist healthcare staff to have education in end-of-life care (EoLC). Much EoLC education is provided by specialist nurses who often have no specific education development to prepare them to teach. To address this gap an Educator Development Programme was developed and delivered to specialist nurses. The authors report on the evaluation of the programme. Two main themes were identified; learning to teach and building skills to change teaching practice. Participants felt more confident and better prepared to teach. Quality EoLC is only possible with a skilled workforce, confident and able to apply the principles of compassionate EoLC to everyday practice. Appropriately trained, specialist staff are better able to teach others how to deliver good quality EoLC. Specialist staff with teaching responsibilities should be provided with, or engage in, continuous professional development to develop their skills and improve their efficacy when teaching. **Abstract:** <https://goo.gl/iNiKVw>

N.B. The Educator Development Programme is an initiative in the U.K. of the Cheshire & Merseyside Palliative & End of Life Care Network Education Strategy Group.

Public policy: An analgesia for opioid diversion

JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY | Online – 24 January 2019 – Although opioids are a commonly prescribed form of analgesics among the armamentarium for their efficacy and safety when used responsibly, societal problems of drug diversion are highly prevalent. This review seeks to examine the importance of opioids and the extent of diversion and its impact, drawbacks, and controversies in law, public policies, and strategies. In particular, the law has skewed its focus toward the regulation of opioid suppliers (as compared to consumers), giving rise to a chilling effect where physicians are hesitant to prescribe opioids to patients with legitimate needs. This has downplayed the importance of medically treating pain, especially in the context of palliative care. This article recommends the intelligent use of public policy to alleviate the opioid diversion problem while acknowledging the importance of appropriate pain management. Concurrently, this article recommends providing continuous education and support for physicians, dispensers, and the like and adoption of soft law approaches by legislators and enforcement bodies to prevent relentless clamping down on opioid abusers. Appropriate policies and guidelines are necessary to support the entire health care body in executing a coordinated approach and exercising vigilance to better manage the opioid diversion problem. **Abstract:** <https://goo.gl/samngL>

Noted in Media Watch 17 September 2018 (#581, p.8):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 10 September 2018 – **‘Ensuring and restoring balance on access to controlled substances for medical and scientific purposes: Joint statement from palliative care organizations.’** The central principle of “balance” represents the dual obligation of governments to establish a system of control that ensures the adequate availability of controlled substances for medical and scientific purposes while simultaneously preventing their non-medical use, diversion, and trafficking, two primary goals of the international control system. This report presents examples of unbalanced systems and a joint statement from global and regional palliative care organizations to promote development of balanced systems for optimal public health outcomes. **Abstract:** <https://goo.gl/JhTRBM>

Pediatric palliative care in the multi-cultural context: Findings from a workshop conference

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 January 2019 – Participants included 142 individuals representing over 6 unique disciplines, 25 of the U.S., and 3 nations. Whereas the conference focused on pediatric palliative care, findings were broadly generalizable to most medical settings. Participants identified key reasons cultural differences may create tension and then provided frameworks for communication, training, and clinical care. Specifically, recommendations included phrases to navigate emotional conflict, broken trust, unfamiliar family values, and conflict. Suggested approaches to training and clinical care included the development of core competencies in communication, history taking, needs assessment, and emotional intelligence. Important opportunities for scholarship included qualitative studies exploring diverse patient – and family – experiences, quantitative studies examining health disparities, and randomized clinical trials testing interventions designed to improve community partnerships, communication, or child health outcomes. Taken together, findings provide a foundation for collaboration between patients, families, and clinicians of all cultures. **Abstract (inc. link to references):** <https://goo.gl/mizEHy>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 January 2019 – **‘The Photographs of Meaning Program for pediatric palliative caregivers: Feasibility of a novel meaning-making intervention.’** Research indicates that informal caregiving can have intense physical and mental impact on the individual. Relative to caregivers of adults, pediatric palliative caregivers appear less in literature despite experiencing greater mental, physical, financial, and social strain. Findings [of this study] suggest that the Photographs of Meaning Program is a practical intervention with life-enhancing potential for pediatric palliative. **Abstract:** <https://goo.gl/35kbnA>

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- *JOURNAL OF PEDIATRIC SURGERY*, 2019;54(1):133-139. ‘**Procedural burden experienced by children with cancer during their terminal hospital admission.**’ This study highlights the magnitude and often short time from invasive procedures to the time of death experienced by children during their terminal hospital admission. It also brings attention to the invasiveness of high-intensity end-of-life care (EoLC) in pediatric-aged patients and the need for open, multidisciplinary discussions regarding the necessity of invasive procedures and for surgeon involvement in the complex EoLC decisions made for terminally ill children with cancer. **Full text:** <https://goo.gl/qWrRnw>
- *NURSE EDUCATION IN PRACTICE* | Online (Inprint) – Accessed 26 January 2019 – ‘**The use of a theatre workshop in developing effective communication in paediatric end-of-life care.**’ The aim of this study was to explore the effectiveness of a novel workshop in teaching transferable knowledge and skills in palliative, end of life and bereavement care communication to a convenience sample of first year pre-registration nursing students undertaking clinical skills training at a U.K. university. The workshop facilitated students’ exploration of how good and poor communication looks and feels and introduced aids to inform communication in clinical practice. **Abstract:** <https://goo.gl/6hkwrB>

Can Death Cafés resuscitate morale in hospitals?

MEDICAL HUMANITIES | Online – 19 January 2019 – Death Cafés are non-profit social franchises that arise spontaneously in communities to serve as informal forums for discussing death. There is a great need within the medical community for the kind of conversation that Death Cafés foster: open, unstructured, spontaneous, genuine and interdisciplinary dialogue. Burnout in healthcare, with symptoms of exhaustion, depersonalisation and decreased efficacy, is a global crisis, with alarming estimates suggesting one in three practicing physicians experience burnout. While open-forum community-based Death Cafés exist widely, there appears to be no evidence in the literature to suggest that healthcare settings have adapted this model for fostering debriefings among hospital employees. The authors introduce the concept of hospital-based Death Cafés as distinct from community-based Death Cafés. From their experience, hospital-based Death Cafés are easy to implement, inexpensive, require little planning and yet offer tremendous reward to participants. Should the phenomenon of Death Cafés take off in hospitals as it has in communities internationally, the authors propose that this intervention be studied for its effect on healthcare worker burnout. **Abstract:** <https://goo.gl/tVNMq8>

N.B. Additional articles on Death Cafés noted in 1 May 2017 issue of Media Watch (#510, pp.8-9).

Early palliative care: Pro, but please be precise!

ONCOLOGY: RESEARCH & TREATMENT, 2019;42:11-18. Many patients suffer from distressing symptoms or problems in early phases of such illness. Therefore, it is not a question of “if” palliative care (PC) should be integrated early into oncology, but “how.” General PC is defined as an approach that should be delivered by healthcare professionals regardless of their discipline. This is often referred to as “general” or “primary” PC. For this, routine symptom assessment, expertise concerning basic symptom management, and communication skills are basic requirements. Communication skills include the willingness to engage in discussions concerning patients’ fears, worries and end-of-life issues without the fear of destroying hope. Specialist PC is provided by specialist teams regardless of the patients’ disease, be it cancer or non-cancer. Such teams should be integrated in the care of PC patients depending on the availability of these services and the patients’ needs. Key messages: “Early PC” must not be used synonymously with “early specialist PC” because much of the PC is delivered as basic oncology PC. For the integration of specialist PC, the identification of triggers is warranted in different institutions to facilitate a meaningful and effective cooperation. Such cooperations should be based on patients’ needs, but must also account for questions of availability and resources. **Abstract (w. list of references):** <https://goo.gl/JfBq1u>

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Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 January 2019 – ‘**ED-PALS: A comprehensive palliative care service for oncology patients in the emergency department.**’ The American College of Emergency Physicians has identified early palliative care (PC) referral for patients with advanced cancer as a key competent of the Choosing Wisely campaign. This tripartite model of PC, hospice and emergency department (ED) collaboration allows earlier access to PC in the ED and direct admissions to the PC unit and comfort care rooms. In this study, the ED patients who did not need admission were also attended to in the PC “hot clinics” within a week with home hospice help. **Abstract:** <https://goo.gl/bkJuXN>
- *ONCOLOGY: RESEARCH & TREATMENT* | Online – 19 January 2019 – ‘**Patients’ preferences in non-curable cancer disease.**’ Eliciting and integrating patients’ preferences in decision-making in palliative oncology is an important criterion for the quality of end-of-life (EoL) care. It is an essential prerequisite in supporting the integrity of patients’ decision-making process, enhancing patients’ right to self-determination and facilitating patients’ autonomy. The authors summarize the data on: 1) Patients’ preference for a decisional model in advanced cancer; 2) Preferences for quality versus length of life and the enrollment of patients in early-phase clinical studies; and, 3) Preferences for caregiver involvement in decision-making. **Abstract (w. list references):** <https://goo.gl/zEgmQ9>

Bereavement service led by senior clinicians may reduce risk of legal action after patient deaths

ONMEDICA | Online – 22 January 2019 – Hospital bereavement services that are led by senior doctors and nurses and the person responsible for quality and safety may help to curb patient complaints and legal action in the wake of a patient death, suggest the results of a pilot study, carried out at one National Health service hospital trust.¹ Families who use hospital bereavement services often do so because they have unanswered questions about the diagnosis or treatment of the person who has died and/or issues around the quality of the care provided, say the researchers. **Full text:** <https://goo.gl/UKvRQo>

1. ‘Simple and powerful: A consultant and governance-led bereavement service,’ *BMJ Supportive & Palliative Care*, published online 10 January 2019. **Abstract:** <https://goo.gl/BygVsT>

Threefold rise in homeless people [in England] visiting A&E

ONMEDICA | Online – 21 January 2019 – The number of visits to emergency departments by homeless people in England has more than trebled since 2011. This is the finding of an investigation by the British Medical Association (BMA), leading to the BMA to declare that society’s most vulnerable people are being let down by the system. Recorded visits to hospital A&E departments by patients classed as having no fixed abode rose from 11,305 in 2011 to almost 32,000 last year. The BMA investigation suggests health and social care cuts are driving the problem. To make matters worse, the homeless patients are presenting with increasingly complex physical and mental health conditions. **Full text:** <https://goo.gl/RHwJUH>

Noted in Media Watch 9 July 2018 (#571, p.4):

- U.K. | *The Independent* (London) – 6 July 2018 – ‘**Terminally ill homeless people are dying on our streets. They deserve dignity like the rest of us.**’ Homeless people attend A&E six times as often as people with a home and are admitted to hospital four times as often, and stay three times as long. Most don’t access the care and support they need in their last few days, weeks and months. A proposed new law aims to provide the clearest possible legal framework for terminally ill homeless people.¹ <https://goo.gl/87q1oS>

1. ‘Homelessness (End-of-Life Care) Bill 2017-19.’ **Download/view at:** <https://goo.gl/vBMSBu>

N.B. A link to a report on the BMA investigation, published in the January 2019 issue of *The Doctor*, is embedded in the *OnMedica* article (click on the word “investigation”). Selected articles on end-of-life care (EoLC) for the homeless in the U.K. noted in 30 April 2018 issue of Media Watch (#561, p.10). 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 6 November 2017 issue of the weekly report (#537, p.5). **Download/view at:** <https://goo.gl/5aygwT>.

End-of-life care in Romania

Quality in palliative care: A critical note and a perspective

PALIAȚIA, 2019;12(1). The overall picture of palliative care (PC) is that it is cost saving in almost all settings, although cost-effectiveness studies maybe criticized because of the variation in design and methods. Given its costs-effectiveness many countries have developed PC, but the variation in the quality of PC is large. This variation has to do with the funding models in PC, but a successful model in one country may not be effective in another one. It seems that in many countries policy makers and involved PC professionals pick up those elements in building up a PC system, which fits them best. They seldom consider an overall view, which needs to include various dimensions, as is demonstrated by the Quality of Death Index.¹ Of course, the quality of PC is not isolated from the way the health care system is organized in a country and the nation's spending on health care and government policy on PC. Looking at that aspect, which is called the "health care environment" dimension, European countries score extremely low, i.e., Bulgaria and Romania. Looking at the dimension "quality of palliative care," which means looking at the presence of painkillers, multidisciplinary teams, accommodations and bereavement services as well as using patients satisfaction surveys, the highest scores are for the U.K., Sweden, Australia, New Zealand, France, Canada and Belgium, while in Europe Hungary, Bulgaria, Romania, Slovakia, Russia, Greece and Ukraine score < 40. Despite these figures, there are recently indicators which may give an optimistic perspective about PC in Romania. For example ... a unified, official regulation on how to organize PC in Romania is established. Part of it is the integration with regular health care services, including strengthening primary health care... **Full text:** <https://goo.gl/p8FDmp>

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' Economist Intelligence Unit. [Noted in 12 October 2015 issue of *Media Watch* (#431, p.6)] Romania was ranked 64th of the 80 countries surveyed. **Download/view at:** <https://goo.gl/PPu7rG>

N.B. Additional articles on palliative and end-of-life care in Romania noted in 16 April 2018 (#559, p.11). Contents page of the current issue of *Paliatia*: <https://goo.gl/zGerqD>

Palliative care in motor neurone disease: Where are we now?

PALLIATIVE CARE: RESEARCH & TREATMENT | Online – 21 January 2019 – Palliative care (PC) has a very important role in the care of patients with motor neurone disease and their families. There is increasing emphasis on the multidisciplinary assessment and support of patients within guidelines, supported by research. This includes the telling of the diagnosis, the assessment and management of symptoms, consideration of interventions, such as gastrostomy and ventilatory support, and care at the end of life. The aim of PC is to enable patients, and their families, to maintain as good a quality of life as possible and helping to ensure a peaceful death. **Full text:** <https://goo.gl/9VKeDf>

Noted in *Media Watch* 25 January 2016 (#446, p.10):

- *BRITISH JOURNAL OF OCCUPATIONAL THERAPY* | Online – 14 January 2016 – '**Existential concerns for people with motor neurone disease: Who is listening to their needs, priorities and preferences?**' The [U.K.] Motor Neurone Disease Association practice guidelines recommend that multidisciplinary health and social care professionals should focus upon psychological, functional and medical management.¹ A referral to the palliative care team is recommended as the disease progresses, if a person experiences a loss of speech or respiratory insufficiency. People living with motor neurone disease have existential concerns from the time of their diagnosis. Valuable opportunities may be lost to discuss and document their needs, priorities and preferences for end-of-life care before a person loses their ability to communicate by any means. **Abstract:** <http://goo.gl/fCY8b3>

1. 'Palliative and end-of-life care,' Motor Neurone Disease Association, 2015. **Download/view at:** <https://goo.gl/RBV4HF>

Advance care planning in the context of clinical deterioration: A systematic review of the literature

PALLIATIVE CARE: RESEARCH & TREATMENT | Online – 19 January 2019 – A Rapid Response Team (RRT) can respond to critically ill patients in hospital to prevent further deterioration and unexpected deaths. However, approximately one-third of reviews involve a patient approaching the end-of-life. It is not well understood whether patients have pre-existing advance care plans at the time of significant clinical deterioration requiring RRT review. Nor is it understood whether such critical events prompt patients, their families and treating teams to discuss advance care planning and consider referral to specialist palliative care (PC) services. Of the 324 articles identified through database searching, 31 met the inclusion criteria, generating data from 47,850 patients. There was a low prevalence of resuscitation orders and formal advance directives (ADs) prior to RRT review, with subsequent increases in resuscitation and limitations of medical treatment orders, but not ADs. There was high short- and long-term mortality following review, and low rates of PC referral. **Full text:** <https://goo.gl/Kf54g2>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 January 2019 – ‘**Adaptation and preliminary validation of the advance care planning engagement survey for surrogate decision makers.**’ Although measures exist that assess patient engagement in the advance care planning (ACP) process, there are no validated tools to assess surrogate decision-makers’ (SDM) role in ACP. The 17-item ACP Engagement Survey for SDMs is a conceptually sound and reliable questionnaire adaptation of the original ACP Engagement Survey.¹ This questionnaire may be used by researchers in parallel with the patient-oriented ACP Engagement survey to more fully understand the impact of ACP interventions on SDMs. **Abstract (inc. link to references):** <https://goo.gl/JTrLhY>

1. ‘Measuring advance care planning: Optimizing the Advance Care Planning Engagement Survey,’ *Journal of Pain & Symptom Management*, 2017;53(4):669-681. **Full text:** <https://goo.gl/crC8dQ>

Hospice and palliative care volunteering in The Netherlands: Practices of “being there”

PALLIATIVE MEDICINE IN PRACTICE, 2018;12(4):193-197. Hospice and palliative care (HPC) volunteering is not easily comparable through European countries. Comparison of practices in different countries helps to acknowledge, protect and improve the core of this unique source in palliative care. To this end this contribution describes volunteering practices at the end of life in The Netherlands. It presents quantitative characteristics about numbers of volunteers, type of hospices and hours worked and a qualitative description of the volunteering work guided by the concept of “being there.” Some reflections on education of volunteers is added. The satisfaction of relatives with services is discussed and some thoughts on quality assurance of volunteering are shared. All information and data in this publication is retrieved from several “grey” documents like mission statements, year reports or registration fact sheets. All describe the Dutch situation of HPC volunteering and are written in the Dutch language. **Abstract (w. list of references):** <https://goo.gl/cnWjD7>

Correlates of perceived death competence: What role does meaning-in-life and quality-of-life play?

PALLIATIVE & SUPPORTIVE CARE | Online – 21 January 2019 – Understanding factors that are associated with more adaptive death attitudes and competencies can inspire future health-promoting palliative care strategies and inform approaches to training and development for health professionals. The potential importance of meaning, purpose, quality and values in life for promoting adaptive death attitudes has been highlighted, but there is limited research in this area, particularly in relation to death competence. The purpose of this study was to develop an understanding of demographic and life-related factors associated with perceived death competence, such as meaning in life and quality of life. The findings demonstrate important interconnections between our attitudes about life and death. Knowledge of factors associated with poorer death competence may help identify those at risk of greater distress when facing death, and might prove useful additions to bereavement risk assessments. Understanding factors associated with greater

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death competence in health professionals and volunteers may help predict or prevent burnout and compassion fatigue, and help identify who would benefit from additional training and support. Future longitudinal studies including both health professionals and the general community are needed to determine the effect adaptive attitudes toward meaning in life can potentially have on bolstering subsequent adaptive coping and competence regarding death and dying. **Abstract (w. list of references):** <https://goo.gl/DWYSEL>

Does silence speak louder than words?

The impact of oncologists' emotion-oriented communication on analogue patients' information recall and emotional stress

PATIENT EDUCATION & COUNSELING, 2019;102(1):43-52. Cancer patients want and need information to make informed decisions and cope with their disease. They generally want detailed information about the disease itself, their prognosis, treatment options, and side-effects. Oncologists are most often preferred as information providers and might therefore be deployed to fulfill those needs. However, patients were found to forget approximately 50% of information during consultations, especially when treatment-related. In view of this considerable loss of information, it is not surprising that cancer patients report unfulfilled information needs that remain during the course of treatment. Therefore, identifying communication strategies for oncologists to improve patients' information recall is imperative. One mechanism by which oncologists' communication could improve information recall is reducing cancer patients' emotional stress... Emotional stress is defined here as the increase in physiological arousal and/or self-reported negative feelings evoked by emotional stimuli, e.g., the provision of bad news. Such emotional stress can be reduced by oncologists' displaying emotional engagement with the patient, e.g., by conveying compassion, or providing reassurance and ongoing support, which was indeed shown to enhance recall. The literature on medical communication skills suggests that oncologists can help patients manage their emotions by explicitly exploring and acknowledging the expressed emotions verbally and/or providing supportive and empathic statements in response to emotions. Silence has been suggested as a non-explicit way to respond to patients' emotions. **Full text:** <https://goo.gl/CiwtMJ>

Noted in Media Watch 12 February 2018 (#550, p.14):

- *ONCOLOGY NURSE ADVISOR* | Online – 8 February 2018 – **'Sitting with silence in end-of-life cancer care.'** The research of Back and colleagues outline three types of silences that can manifest between patients and clinicians in the clinical encounter: awkward, invitational, and compassionate.¹ In regard to awkward silences, they write, "silence most often feels like it is dragging on too long when a well-meaning clinician thinks he should be 'using silence.'" While we recognize that new skills have a learning curve before they can be performed smoothly, we also think that the problem with a directive to stop doing something is unlikely to produce the quality of silence that is actually therapeutic." **Full text:** <https://goo.gl/U7Nrs4>

1. 'Compassionate silence in the patient-clinician encounter: A contemplative approach,' *Journal of Palliative Medicine*, 2009;12(12):1113-1117. [Noted in 24 August 2009 issue of Media Watch (#111, p.5)] **Abstract:** <https://goo.gl/DNuVxy>

Noted in Media Watch 14 August 2017 (#525, p.5):

- *PALLIATIVE MEDICINE* | Online – 8 August 2017 – **'Silence as an element of care: A meta-ethnographic review of professional caregivers' experience in clinical and pastoral settings.'** Silence is acknowledged as integral to interpersonal communication and compassionate care, but is also noted as a complex and ambiguous phenomenon. International, interdisciplinary research and opinion endorses the value of silence in clinical care. As a multi-functional element of interpersonal relationships, silence operates in partnership with speech to support therapeutic communication. As a caregiving practice, silence is perceived as particularly relevant in spiritual and existential dimensions of care when words may fail. **Abstract:** <https://goo.gl/aXHib8>

Social representation of palliative care in the Spanish printed media: A qualitative analysis

PLOS ONE | Online – 25 January 2019 – Lack of social awareness is a major barrier to the development of palliative care (PC). Mass media influences public opinion, and frequently deal with PC contributing to its image and public understanding. Politician and healthcare professionals were the main representatives transmitting messages on PC. The discourses identified were characterised by: strong ideological and moral content focusing on social debate, strong ties linking PC and death and, to a lesser degree, as a healthcare service. The messages transmitted by representatives with direct experience in PC (professionals, patients and families) contributed the most to building a positive image of this healthcare practice. Overall, media reflect different interests in framing public understanding about PC.

The knowledge generated about how PC is reflected in the printed media may help to understand better one of the main barriers to its development not only in Spain, but also in other contexts. **Full text:** <https://goo.gl/Yw23vV>

Oxford Textbook of

Palliative Medicine

'Communications with the Public, Politicians and News Media,' **Full text:** <https://goo.gl/F4TR4J>

Access to palliative care in rural Wisconsin

WISCONSIN MEDICAL JOURNAL, 2018;117(5). A 2015 report from the Center to Advance Palliative Care demonstrated the importance of palliative care (PC).¹ This report highlighted the need for each state to "create a multidisciplinary advisory board and/or task force to conduct a landscape analysis of available PC services to determine state capacity and develop appropriate recommendations for improving access to quality PC." One of the most significant findings of an environmental scan focused on rural counties in Wisconsin... The 2017 Rural Wisconsin Health Report identified 46 of 72 counties (65%) as rural. However, only 26% of the Wisconsin population resides within a rural county. Eighty-one hospice organizations are in the state. Surveyed hospitals and members of the Palliative Care Network of Wisconsin indicated the presence of 33 PC organizations in Wisconsin. The only county without a known PC organization is Pepin, which lies in the Western region along the border with Minnesota. **Full text:** <https://goo.gl/bboQDT>

1. 'America's Care of Serious Illness: 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals,' Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. [Noted in 5 October 2015 issue of Media Watch (#430, p.14)] **Download/view at:** <https://reportcard.capc.org/>

N.B. Selected articles on the provision and delivery of hospice and palliative care services in rural America noted in 14 January 2019 issue of Media Watch (#597, p.3).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *RELIGIONS* | Online – 22 January 2019 – '**Good deaths: Perspectives in dying well and on medical assistance in dying at Thrangu Monastery Canada.**' Anthropological, sociological, and bio-ethical research suggest that various agencies affect one's relationship with the dying process and end-of-life decisions. Agencies include the media, medical professionals, culture, and religion. Observing the prevalence of meditations and rituals relating to death at Thrangu Monastery Canada, the author wanted to investigate how the latter two agencies in particular, namely culture and religion, impacted the monastery members' views on the dying process. During 2018 interviews, she asked their opinions on the meaning of dying well, and on medical assistance in dying (MAiD), which was legalized in Canada in 2016. Although some scriptural examinations have suggested that voluntary euthanasia is contrary to Buddhist teachings, the majority of the monastery's respondents support MAiD to some degree and in some circumstances. Moral absolutes were not valued as much as autonomy, non-interference, wisdom, and compassion. **Abstract:** <https://goo.gl/GC5NB3>

Publishing Matters

A new strategy to hoist predatory journals and publishers

INTERNATIONAL JOURNAL OF SURGERY OPEN | Online – 19 January 2019 – The trend through which academia finances scientific publication has been changed into open access publishing, the latter exploited by predatory journals and publishers. Kscien has recruited a special committee consisting of 23 young researchers. They are working unceasingly to keep the list refurbished, expose current tricks invented by the predators and guide authors. The list is designed to be updated daily. Currently, the criteria used to recognize predatory journals and publishers are basically depend on the journal's misconduct, fabrication and inadequate peer review. Researches are ongoing to recapitulate more solid criteria with objective evidences to overcome the critics faced by Beall. Kscien's list has been proposed to replace vanished Beall's list from the interior of the drawn region in fake journals and publishers. **Full text:** <https://goo.gl/BiMZrK>

N.B. Kscien website: <https://goo.gl/cvS7cR>; about Kscien <https://goo.gl/ygZ2BQ>

The hunter became the hunted: A graduate student's experiences with predatory publishing

PUBLISHING RESEARCH QUARTERLY | Online – 17 January 2019 – As predatory publishing has influenced the educational research community, this study sought to understand and articulate current predatory publishing practices which may render important academic research “post-truth” or “fake news” if authors are not careful where they publish and with whom. Findings suggest predatory publishers obscure publication charges, steal identities of real scholars and position them as editors of predatory journals, mimic website aesthetics of credible journals, and gather author information to further promote predatory publishing and fake academic conferences. Future research and viability of open-access publishing are addressed, as well as a discussion of academic publishing, predatory publishing, and the pressure graduate students and junior researchers often experience during the “publish or perish” process of tenure and promotion. **Abstract (w. list of references):** <https://goo.gl/uL6T5v>

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.

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

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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 ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/82W1Wo>

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PALLIATIVE CARE NETWORK: <https://goo.gl/YBP2LZ>

PALLIMED: <http://goo.gl/7mrqMQ>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at <https://goo.gl/6vdk9v>]

Asia

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

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

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

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://goo.gl/SyTuQ7>

HUNGARY | Magyar Hospice Alapítvány: <https://goo.gl/L7D2hw>

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>

United States

NEBRASKA | Center for Health Policy & Ethics, Creighton University: <https://goo.gl/JVEprv>

[Scroll down to 'Barry Ashpole's Media Watch']

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