

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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Direct interaction between palliative and interdisciplinary teams in clinical practice is the key factor in the education of health care professionals, in the development of a “palliative attitude,” and in the promotion of palliative medicine.

‘Perception of palliative medicine by health care professionals at a teaching community hospital: What is the key to a “palliative attitude?”’ (p.10), in *Journal of Multidisciplinary Healthcare*.

U.S.A.

A shortage of end-of-life doctors is coming

FORBES | Online – 4 June 2019 – A declining number of physicians specialized in palliative care (PC) looms and won’t recover for 25 years without major U.S. health policy changes, new research shows.¹ Research ... shows about one-third of PC clinicians are burned out and about two in five are 56 years of age or older, making a shortage almost certain to begin in less than a decade. Currently, there are about 7,600 physicians who are board certified in PC generally and have completed a fellowship and come from a variety of medical disciplines including pulmonology, oncology and primary care. But those numbers of PC specialists, who are an integral part of a team when treating seriously ill patients, aren’t increasing in number. “Our modeling revealed an impending ‘workforce valley,’ with declining physician numbers that will not recover to the current level until

2045, absent policy change,” Arif Kamal, a medical oncologist and palliative medicine specialist at Duke Cancer Center, and his fellow researchers wrote in their analysis... <http://bit.ly/2wxcaXS>

Specialist Publications

‘How should physicians respond to patient requests for religious concordance?’ (p.5), in *AMA Journal of Ethics*.

‘Caregiver care’ (p.6), in *American Family Physicians*.

‘Top ten tips palliative care providers should know about caring for veterans’ (p.12), in *Journal of Palliative Medicine*.

1. ‘Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,’ *Health Affairs*, 2019;38(6):910-918. **Full text:** <http://bit.ly/2QMAU7N>

N.B. The focus of the current issue of *Health Affairs* is community care for high-need patients. **Journal contents page:** <http://bit.ly/2wAakp9>

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Noted in Media Watch 19 February 2018 (#551, p.6):

- *AMERICAN JOURNAL OF MEDICAL QUALITY* | Online – 7 February 2018 – ‘**Hospice care needs study.**’ Medical schools have attempted to integrate hospice and palliative medicine (HPM) curricula for more than 20 years... Despite these initiatives, gaps in both education and numbers of qualified providers still exist, and hospice remains largely misunderstood by patients and medical professionals alike. A task force convened by the American Academy of Hospice & Palliative Medicine found an acute shortage of HPM physicians and reported that current fellowship programs are insufficient to fill the shortage. **First page view:** <http://bit.ly/2Wn6qPO>
 1. ‘Estimate of current hospice and palliative medicine physician workforce shortage,’ *Journal of Pain & Symptom Management*, 2012;40(6):899-911. (Noted in 13 December 2010 issue of Media Watch, #179, p.9.) **Full text:** <http://bit.ly/2QNii7Q>

Noted in Media Watch 5 February 2018 (#549, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 February 2018 – ‘**The growing demand for hospice and palliative medicine physicians: Will the supply keep up?**’ The current U.S. supply of hospice and palliative medicine (HPM) specialists is 13.35 per 100,000 adults 65 and over. This ratio varies greatly across the country. Using alternate assumptions for future supply and demand, the authors project need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. Supply will range from 8,100 to 19,000. Current training capacity is insufficient to keep up with population growth and demand for services. **Full text:** <http://bit.ly/2CRjxwO>

International

End-of-life care in Ireland

Uncertainty continues around State funding for Marymount hospice

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 7 June 2019 – Ireland’s oldest and largest hospice has launched a seven-year strategic plan against the backdrop of ongoing uncertainty over the level of its State funding. Marymount University Hospital and Hospice in Cork, which serves a population of more than 500,000 people and which depends on the State for nearly 60% of its income, described their 2019-2025 strategic plan ... as an “ambitious but cost-effective plan” to deliver excellence in caring for the elderly and in providing specialist palliative care (PC). Kieran Barry, chairman of the board of directors, said the economic case for investment in services for older people and for specialist hospice care is well established and the strategy launched ... has been formulated to address gaps in services. Marymount chief executive officer, Sarah McCloskey, said new evidence shows that PC is not only clinically effective

and prolongs life, but is equally cost-saving: “In the UK, they have estimated that approximately 20% of acute hospital bed days are taken up by end-of-life care.” But the hospice confirmed that engagement with the Health Service executive over the level of State funding is ongoing. <http://bit.ly/2ZjbbHh>

Specialist Publications

‘**Access to palliative care for cancer patients between diagnosis and death: A national cohort study**’ (p.7), in *Clinical Epidemiology*.

‘**Consensus building on health indicators to assess palliative care global development with an international group of experts**’ (p.11), in *Journal of Pain & Symptom Management*.



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Thousands of cancer patients die in Armenia without receiving palliative care

ARMENIA | Armenia News Agency (Yerevan) – 6 June 2019 – According to the director of the Europe & Central Asia Department of Human Rights Watch, Giorgi Gogia, about 8 thousand people die from cancer annually in Armenia. “80% of them die in conditions of extreme pain, and they need opioid analgesics,” he told reporters... Meanwhile, the number of opioid drugs in Armenia is not enough. “Even if all the available drugs are combined, only 2% of those who die of cancer will be able to receive palliative care (PC),” Gogia said. Gogia notes that the government of Armenia made a significant contribution to the implementation of PC, especially from the point of view of legislative initiatives. However, when opioid analgesics are prescribed, oncologists in Armenia continue to be guided by the outdated regulations for 1994, ignoring the new recommendations that meet international standards. <http://bit.ly/2MxnH4b>

Noted in Media Watch 20 February 2017 (#500, p.5):

- ARMENIA | Human Rights Watch – 16 February 2017 – ‘**Armenia’s new strategy to help those in pain.**’ About 8,000 people die from cancer in Armenia every year, many spending their last days in excruciating pain. But Armenia is taking an important step towards ending their suffering and the government recently adopted a national strategy to introduce palliative care services. When curative treatment is no longer effective, patients with advanced cancer in Armenia are simply sent home. Abandoned by the health care system at arguably the most vulnerable time of their lives, people with life-limiting illnesses face pain, fear, and anguish without professional support. <http://bit.ly/31gLHvJ>

Public submissions to Queensland inquiry into aged care, palliative care and voluntary assisted dying seem focus on end-of-life decisions

AUSTRALIA (Queensland) | *The Weekly Source* (Balmain East, New South Wales) – 4 June 2019 – The inquiry was initially announced by the Queensland Parliamentary Health, Communities, Disability Services and Domestic and Family Violence Committee in November 2018 (within a month of the Royal Commission) and received more than 5,000 submissions before the deadline in April. While the submission scope included aged care, an initial glance at the first 500 suggests Queenslanders are mostly concerned with end-of-life and palliative care issues rather than home or residential aged care. The inquiry is hosting a series of public community forums across the state to receive more submissions from the community. <http://bit.ly/2WadhqJ>

Shock for families as children’s hospice set to close

U.K. (England) | *The Shropshire Star* (Telford) – 4 June 2019 – Children’s charity Acorns is to close one of its three hospices because of rising running costs and a drop in donations. The charity will stop providing care at the unit from the end of September, if the proposal goes ahead. The news was today being broken to families and members of staff by chief executive Toby Porter. Acorns has three specialist children’s hospices, providing care and support to youngsters and their families from around the region including Shropshire, the West Midlands and Staffordshire. The charity is currently supporting 233 families at its Walsall unit, which has been earmarked for closure. They will be offered the chance to attend either of the hospices in Birmingham and Worcester. A total of 70 full-time and part-time staff at the Walstead Road hospice face losing their jobs. It costs the charity nearly £10 million every year to provide its services and it relies on fundraising for the bulk of this amount. <http://bit.ly/2WljMw7>

Noted in Media Watch 20 May 2019 (#614, p.5):

- U.K. (England) | *The Shropshire Star* (Telford) – 14 May 2019 – ‘**£250,000 cut to Telford hospice’s grant was “necessary,” says health boss.**’ The decision to cut funding to Severn Hospice by nearly a quarter was necessary in a “particularly challenging financial year,” a local National Health Service chief has said. Telford & Wrekin Clinical Commissioning Group’s annual grant to Severn Hospice stood at £1.1 million for three years, but goes down to £850,000 from 2019-2020. In response, the charity is to close two beds at its Telford in-patient centre at Apley Castle. <http://bit.ly/30fywLf>

“Two converging fronts” spark fears for end-of-life doctors

AUSTRALIA (Queensland) | *The Brisbane Times* – 3 June 2019 – Doctors in palliative and aged care facilities may be walking away from their fields out of fear of being punished for overprescribing opioids or accused of facilitating voluntary assisted dying. Anecdotal evidence of a “perfect storm” of “two converging fronts” – a national crackdown on high prescription rates for opioids, and fears of palliative care being misconstrued as assisted dying – shows some practitioners are scared of being falsely accused when trying to provide quality care to their patients. Queensland Professor Geoffrey Mitchell, along with peers from Queensland University of Technology, the University of New England and the University of Technology Sydney studied the consequences of these two issues in a new paper.¹ The paper concluded that in Australia, out of 12 death cases taken to court, no doctor had been criminally charged. The researchers found

only two of the cases had adverse findings recorded... “This indicates that regulatory bodies are not seeking to blame practitioners when death occurs in the presence of opioid administration, and that the intention to alleviate suffering and adhere to good clinical practice is respected,” the researchers concluded. Last year the federal Health Department wrote to 5,000 doctors in the top 20% of opioid prescribers warning their prescriptions were being scrutinised. <http://bit.ly/2KowZx0>

Specialist Publications

‘That was then, this is now: Using palliative care principles to guide opioid prescribing’ (p.12), in *Journal of Palliative Medicine*.

1. ‘A perfect storm: Fear of litigation for end-of-life care,’ *Medical Journal of Australia*, published online 8 May 2019. (Noted in 20 May 2019 issue of *Media Watch*, #614, p.14.) **Access article at:** <http://bit.ly/2E4fCNX>

N.B. Additional articles on opioid use in the context of palliative and end-of-life care noted in 28 January 2019 and 31 December 2018 issues of *Media Watch*, #599, p.10 and #595, pp.5,19, respectively.

Doctors are warned that learning disability or Down’s Syndrome is no reason not to resuscitate a patient

U.K. | *The Sunday Times* – 12 May 2019 – Doctors should never put a “do not resuscitate” order on a patient simply because they have learning difficulties, a leaked report recommends. The annual report from the Learning Disabilities Mortality Review (LeDeR) programme, which has not yet been published but has been seen by *The Sunday Times*, reveals that 19 patients who later died had “learning disabilities” or “Down’s syndrome” given as the reason not to resuscitate them between July 2016 and December 2018. The scale of the issue may be much bigger, however, as reviews into only a quarter of the 4,302 deaths reported to LeDeR had been completed by the end of last year. LeDeR was set up in 2015 to help local authorities review the deaths of people with learning disabilities... <http://bit.ly/2WoQe0w>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (Victoria) | *The Conversation* – 6 June 2019 – ‘**We don’t know all the details of how voluntary assisted dying will work yet – but the system is ready.**’ Voluntary assisted dying becomes a lawful choice for Victorians from 19 June. To be eligible, two doctors must assess a person to have an incurable, advanced and progressive medical condition that will cause death within six months (or 12 months for neurodegenerative conditions). With Victoria being the first state in Australia to allow voluntary assisted dying, this represents a major shift in end-of-life care. In the 18 months since the law was passed, an Implementation Taskforce has overseen the creation of new resources for the community, clinical guidance and training for health professionals, and policies to help health services decide what care they will provide. While this preparation is critical, there are some questions we’ll only be able to answer once voluntary assisted dying becomes a clinical reality. <http://bit.ly/2HX5etu>

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- AUSTRALIA | Palliative Care Australia (PCA) – 3 June 2019 – ‘**Palliative Care Australia publishes guiding principles for health professionals about voluntary assisted dying.**’ The association has released a set of seven principles to guide health professionals providing care to people living with a life-limiting illness ahead of the Victorian Voluntary Assisted Dying scheme beginning on 19 June 2019. ‘Voluntary Assisted Dying in Australia: Guiding principles for those providing care to people living with a life-limiting illness’ is national in scope, designed to sit alongside enacted state legislation where it exists, organisational ethical frameworks and professional codes of conduct. One of the recommendations from the PCA Board Delegation’s study tour of Canada and the U.S. in late 2018 was that PCA provide national leadership by developing a set of guiding principles to support health professionals in this area. The two key reasons for developing the principles are to ensure that appropriate care is provided to people living with a life-limiting illness at all times, and to ensure that respectful and cooperative relationships between health professionals are maintained. While the practice of palliative care (PC) does not include voluntary assisted dying, as PC doesn’t hasten or postpone a person’s death, people exploring voluntary assisted dying options must be able to continue to receive PC. **Download/view at:** <http://bit.ly/2HW3b9a>

Specialist Publications

How should physicians respond to patient requests for religious concordance?

AMA JOURNAL OF ETHICS, 2019;21(6):E485-E492. In which ways and in which circumstances should institutions and individual physicians facilitate patient-physician religious concordance when requested by a patient? This question suggests not only uncertainty about the relevance of particular traits to physicians’ professional roles but also that medical practice can be construed as primarily bureaucratic and technological. This construal is misleading. Using the metaphor of shared language, this article contends that patient-physician concordance is always a question of degree and that greater concordance can, in certain circumstances, help to obtain important goals of medicine. **Full text:** <http://bit.ly/2JSClvf>

Noted in Media Watch 11 March 2019 (#605, p.8):

- *CANCER* | Online – 2 March 2019 – ‘**A scale to assess religious beliefs in end-of-life medical care.**’ In this study the authors introduce and evaluate the Religious Beliefs in End-of-Life Medical Care scale, a new measure designed to assess religious beliefs within the context of end-of-life (EoL) cancer care. The scale has proved to be internally consistent, unidimensional, positively associated with other indicators of patients’ religiousness and spirituality, and inversely associated with patients’ terminal illness understanding and acceptance, suggesting its potential clinical usefulness in promoting informed EoL decision making. **Abstract:** <http://bit.ly/2ITgxFF>

N.B. Additional articles on religious and spiritual beliefs in the context of EoL care noted in this issue of Media Watch.

Publishing Matters

‘**Three randomized controlled trials evaluating the impact of “spin” in health news stories reporting studies of pharmacologic treatments on patients’/ caregivers’ interpretation of treatment benefit**’ (p.14), in *BMC Medicine*.

‘**Linguistic differences between well-established and predatory journals: A keyword analysis of two journals in political science**’ (p.15), in *Learned Publishing*.

‘**Blacklists and whitelists to tackle predatory publishing: A cross-sectional comparison and thematic analysis**’ (p.15), in *mBIO*.

Caregiver care

AMERICAN FAMILY PHYSICIANS, 2019;99(11):699-706. Eighty percent of adults requiring long-term care currently live at home in the community, and unpaid family caregivers (FCGs) provide 90% of their care. FCGs serve as a critical extension of the U.S. health care system, and the demand for FCGs is expected to increase during the next few decades. Caring for loved ones is associated with several benefits, including personal fulfillment; however, caregiving is also associated with physical, psychological, and financial burdens. Family physicians can aid in the identification, support, and treatment of caregivers by offering caregiver assessments – interviews directed at identifying high levels of burden – as soon as caregivers are identified. Repeat assessments may be considered when there is a change in the status of the caregiver or the care recipient. Caregivers should be directed to appropriate resources for support, including national caregiving organizations, local elder care agencies, websites, and respite care. Psycho-education, skills training, and therapeutic counseling interventions for caregivers have shown small to moderate success by decreasing caregiver burden and increasing caregiver quality of life. Additional research is needed to further identify strategies to offset caregiver stress, depression, and poor health outcomes. Support and anticipatory guidance for the caregiver is especially helpful during care transitions and at the care recipient's end of life. **Abstract:** <http://bit.ly/2WECgXH>

N.B. See related “handout” on caregiver care, written by the authors of this article: <http://bit.ly/2WJKJZz>

Related

- *HEALTH AFFAIRS*, 2019;38(6):964-972. ‘**Spousal caregivers are caregiving alone in the last years of life.**’ Using information from the Health & Retirement Study, the authors found that 55% of the spouses of community-dwelling married people with disability were solo caregivers. Solo caregiving was even common among people who cared for spouses with dementia and those with adult children living close by. While some [U.S.] state and federal policy proposals aim to systematically recognize and assess caregivers, further innovations in care delivery and reimbursement are needed to adequately support seriously ill older adults and their caregivers. Ultimately, the focus of serious illness care must be expanded from the patient to the family unit. **Full text:** <http://bit.ly/2IICPwc>

N.B. The focus of the current issue of *Health Affairs* is community care for high-need patients. Journal contents page: <http://bit.ly/2wAakp9>

- *BRITISH JOURNAL OF COMMUNITY NURSING* | Online – 5 June 2019 – ‘**Barriers and facilitators to implementing the Carer Support Needs Assessment Tool in a community palliative care setting.**’ Palliative care (PC) nurse specialists from two community nursing teams in Lothian, Scotland were interviewed. They acknowledge the importance of carers in PC and encourage carer support practices. Nurses perceived the Carer Support Needs Assessment Tool (CSNAT) as useful, but used it as an “add-on” to current practice, rather than as a new approach to carer-led assessment. Further training is recommended to ensure community palliative care nurses are familiar with the broader CSNAT approach. **Abstract:** <http://bit.ly/2Mzuw5i>

Improving quality in hospital end-of-life care: Honest communication, compassion and empathy

BMJ OPEN QUALITY | Online – 31 May 2019 – With over half of expected deaths occurring in acute hospitals, and a workforce not trained to care for them, good quality end-of-life care (EoLC) in these settings is hard to achieve. The National Consensus Statement on Essential Elements for Safe & High-Quality End-of-Life Care has been translated into e-learning modules by the End-of-Life Essentials project,^{1,2} and this study aimed to demonstrate how clinicians interpret the Consensus Statement in their day-to-day practice by answering the question at the end of each module: ‘Tomorrow, the one thing I can change to more appropriately provide EoLC is...’ Five themes emerged: 1) Communication; 2) Emotional insight; 3) Professional mindset; 4) Person-centred care; and, 5) Professional practice. Learners who have completed End of Life Essentials have shared the ways they state they can change their practice tomorrow which may well be ap-



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preciated as a clinical response to the work by the Australian Commission on Safety & Quality in Health Care in leading and coordinating national improvements in quality and safety in healthcare in Australia. While intent cannot guarantee practice change, theory on intention – behaviour relations indicate that intentions have a strong association with behaviour. This indicates that the modules have the ability to influence EoLC in acute hospitals. **Abstract:** <http://bit.ly/2wE8ofc>

1. 'National Consensus Statement on Essential Elements for Safe & High-Quality End-of-Life Care,' Australian Commission on Safety & Quality in Health Care, December 2016. **Download/view at:** <http://bit.ly/2Z81RFZ>
2. 'End-of-Life Essentials,' Flinders University. **Download/view at:** <http://bit.ly/2wHZL3e>

Palliative care in France

Access to palliative care for cancer patients between diagnosis and death: A national cohort study

CLINICAL EPIDEMIOLOGY | Online – 5 June 2019 – To the best of the authors' knowledge, this is one of the few studies worldwide to explore the proportion of cancer patients with palliative care (PC) access before death in large population databases, to identify socio-demographic and clinical factors associated with this differentiated access and to examine the time between PC access and death. The findings revealed that more than half of the cancer patients included in the French cancer cohort who died between 2013 and 2015 had access to inpatient PC. However, access differed according to socio-demographic and medical characteristics. More specifically, women, younger patients, individuals with cancer of the nervous system, patients with a metastatic cancer, and those with fewer comorbidities, were the most likely populations to have access. Furthermore, the authors found substantial regional variations. With regard to the timing of PC, the results of this study suggest that access to inpatient PC in France occurs late in the disease trajectory. **Full text:** <http://bit.ly/31d250f>

Improving family intensive care unit experiences at the end of life: Barriers and facilitators

CRITICAL CARE NURSE, 2019;39(3):52-58. Experiencing the end of life (EoL) of a family member in the intensive care unit is clearly difficult. An important role of critical care nurses is to help family members through this challenging period. This article highlights a few clinically significant barriers and facilitators related to improving family experiences at the patient's EoL that have received less attention in the literature thus far. Facilitators include specific aspects of communication, the nurse's role as the coordinator of care, bereavement care, promoting a "good death," and caring for health care providers. Barriers include medical uncertainty and differences in values and culture. **Abstract:** <http://bit.ly/2WluFr4>

Noted in Media Watch 11 March 2019 (#605, p.9):

- *INTENSIVE CARE MEDICINE* | Online – 7 March 2019 – '**Eight things we would never do regarding end-of-life care in the ICU.**' As intensivists from three distinct regions of the world [i.e., the U.S., France, Israel] with different cultural backgrounds, the authors believe it relevant in this rapidly emerging period of healthcare to share thoughts among clinicians providing end-of-life care (EoLC) in the intensive care unit. This article presents the authors' vision of eight top-tier concepts that should be embraced to usher in the best EoLC for all patients. The authors realize that not everyone will agree with these points and anticipate that our "eight things" will stimulate healthy discussion and debate. **Abstract (w. list of references):** <http://bit.ly/2XHEB1L>



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

Life Café. A co-designed method of engagement

THE DESIGN JOURNAL | Online – 31 May 2019 – The last decade has witnessed a demographic change on unprecedented scale – people are living longer and with more complex, long term conditions. The authors present a programme which seeks to rethink how palliative and end-of-life (EoL) care can be provided equitably, efficiently and sustainably for future generations. They explore the methodological approach undertaken by university researchers, to engage communities in conversations around a topic often seen as taboo. The community engagement focuses on understanding what is important to individuals in life, care and EoL. A methodology, named the Life Café, has been developed to gather research in an informal manner within community groups and familiar environments. The Life Café comprises critical artifacts, activities and resources, co-developed with community members developed to answer the research questions. The Life Café has become a product that can be used across different services to establish what matters to individuals and enable difficult conversations. **Abstract:** <http://bit.ly/2Z4Ae0r>

When adolescents may die

JOURNAL OF CLINICAL ETHICS, 2019;30(2):77-88. The author discusses how clinicians might best treat adolescents who may die. He discusses: 1) These patients' cognition, emotional tendencies, and sensitivity to interpersonal cues; 2) Their parents' feelings of loss and guilt and their clinicians' risk of imposing their own moral views without knowing this; 3) The practical concerns of helping these patients gain or regain resilience and to identify strengths they have had in the past; and, 4) Who, among staff, might be best able to do this. The author highlights as the main goal that patients, their parents, and ideally also their clinicians are able to come to agree on the best course the patients should take. **Abstract:** <http://bit.ly/2FpPSLx>

Who is the patient? Tensions between advance care planning and shared decision-making

JOURNAL OF EVALUATION IN CLINICAL PRACTICE | Online – 7 June 2019 – Advance care planning (ACP) is commonly viewed as a form of shared decision-making between carers and patients who anticipate losing decision-making capacity. What is unclear in this situation is the identity status of an individual who has become mentally incapacitated and how to evaluate their rights and interests. This is known as the identity problem of ACP. The author suggests that the identity problem can be most convincingly addressed by understanding ACP based on narrative views of identity. These views, however, create a tension in the current medico-legal framework for attributing decision-making capacity. Current laws and guidelines favour maximum inclusiveness and hence mandate supported decision-making of those with reduced or only focally preserved decision-making capacity. Yet, an ACP framework based on narrative identity and the relevant capacities to construct such narratives results in more demanding capacity requirements than current medico-legal practice requires. The law thus espouses conflicting views as to who can be an appropriate decision-making authority for patient care. The author, therefore, concludes that the law governing medical care needs to be clearer about how to resolve the identity problem and revisit its position on ACP or supported decision-making for those who have only focally preserved decision-making capacity. **Abstract:** <http://bit.ly/2lyfXJY>

Related

- *JOURNAL OF CLINICAL ETHICS*, 2019;30(2):131-42. **'Physicians' perspectives on adolescent and young adult advance care planning: The fallacy of informed decision making.'** This study identified two categories important to the utility of advance care planning (ACP) in pediatric hematopoietic stem cell transplant (HSCT) patients: 1) The temporal context of ACP and decision making; and, 2) The limitations of pediatric ACP, with sub-categories identified as a) embodied and witnessed knowing, b) the impact of clinical cascades ... and a creation of a "new normal" following complications of illness and its treatment in the pediatric intensive care unit; c) The balancing of adolescents' autonomy with their capacity to make informed medical decisions; and, d) The epistemological frames that differ between health care professionals and patients and their families. **Abstract:** <http://bit.ly/2FpPSLx>

Cultural appropriateness in health communication: A review and a revised framework

JOURNAL OF HEALTH COMMUNICATIONS | Online – 28 May 2019 – A revised framework for cultural appropriateness is offered on the basis of a systematic review of operationalizations in 44 cancer screening interventions for Asian Americans. Studies commonly conveyed the epidemiological bases of the intervention (97.7%) and used the language of the population (95.5%). Less commonly reported were strategies central to health communication: cultural features of the intervention messages (77.3%) and the cultural beliefs and values that the intervention focused on (43.2%). Few used cultural tailoring (4.5%) and none aimed to address acculturation or cultural identity. The theoretical framework most frequently used was the health belief model (27.3%), which does not explain the role of culture. More studies focused on cultural barriers (20.5%) than cultural strengths (9.1%). The authors' revised framework comprises six cultural appropriateness strategies of cultural identity, linguistic, perceptual features, content, constituent-involving, and socioeconomic context-adaptive. It prioritizes cultural identity to recognize the dynamics within racial ethnic groups and to inform adaptive efforts for cultural appropriateness. It emphasizes examining cultural strengths that can facilitate change, as well as reducing cultural barriers. Future research and action should address the disparities in extant health disparities research in which theory and methods are underdeveloped and underutilized for Asian Americans. **Abstract:** <http://bit.ly/2W8psEK>

Noted in Media Watch 24 September 2018 (#582, p.7):

- *AUSTRALIAN CRITICAL CARE* | Online – 17 September 2018 – '**Culturally sensitive communication at the end of life in the intensive care unit: A systematic review.**' Culturally sensitive communication (CSC) is not well defined or translated into clinical practice. It is dependent on the values and beliefs of individual clinicians and has multiple contributing factors. There are challenges related to communication and similarities and differences between how nurses and physicians communicate. The findings of this study also emphasise issues related to the knowledge deficit of clinicians in demonstrating CSC and the need for further education. **Full text:** <http://bit.ly/2QDXvDy>

A digital pain management tool for informal caregivers in home hospice

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(3):193-199. Informal hospice caregivers often have difficulty managing patient pain at home. The authors developed a digital application, e-Pain Reporter, for informal caregivers to record and providers to monitor patient pain and pain management. Feasibility of the e-Pain Reporter was assessed by the average number of times caregivers recorded breakthrough and daily pain and caregiver satisfaction with the app. Caregivers [i.e., study participants] reported high overall satisfaction with the e-Pain Reporter. Barriers scores were moderately high, suggesting erroneous beliefs and misconceptions about pain reporting and use of analgesics, but self-efficacy in managing pain was also high. Findings suggest that the e-Pain Reporter is a feasible method to report and monitor caregiver management of pain at home. **Abstract:** <http://bit.ly/2KplHIG>

Noted in Media Watch 18 February 2019 (#602, p.13):

- *MEDSCAPE* | Online – 13 February 2019 – '**Dying at home: The burden of medication management.**' A recent literature review explored the experiences and perspectives of family caregivers in managing medications for a family member being cared for and dying at home.¹ The authors reviewed 15 studies in this area and synthesized the findings into five key themes that provide a framework to improve support for these caregivers: These concepts provide important perspectives on caregiver fears, such as overmedicating the patient, and challenges in understanding instructions, particularly with multiple medications. **Full text:** <https://wb.md/2X43MeD>

1. 'Managing medicines for patients dying at home: A review of family caregivers' experiences.,' *Journal of Pain & Symptom Management*, published online 11 September 2018. (Noted in 17 September 2018 issue of Media Watch, #581, p.12.) **Full text:** <http://bit.ly/2tli8t8>

Perception of palliative medicine by health care professionals at a teaching community hospital: What is the key to a “palliative attitude”?

JOURNAL OF MULTIDISCIPLINARY HEALTH-CARE | Online – 5 June 2019 – Results of the two studies were essentially similar. On most of the issues, survey respondents’ perceptions were consistent with palliative medicine (PM) concepts and confidence in palliation grew over the 14-year study period. The authors call this approach a “palliative attitude.” Physicians with greater experience performed better in care planning. Younger physicians were more perceptive to withdrawal of care in futile cases. Participants’ religion had no influence on perception of PM. Attendance of educational activities did not influence attitudes of health care professionals. Health care providers who favored involvement of palliative care teams in patients’ management were better in care planning, interpretation of the DNR consent, use of opioids at the end of life, use of intensive care, and evaluation of the disease trajectory. The authors conclude that direct interaction between palliative and interdisciplinary teams in clinical practice is the key factor in the education of health care pro-

professionals, in the development of a “palliative attitude,” and in the promotion of PM. **Full text:** <http://bit.ly/2HXh6Mc>

Care Redesign Survey: The power of palliative care

NEJM CATALYST | Online – 6 June 2019 – The *NEJM* Catalyst Insights Council survey on palliative care (PC) reveals an interesting dichotomy: While the great majority of organizations have a palliative or end-of-life care program, 60% of patients who would benefit from such services don’t receive them. The survey finds that non-profit health care delivery organizations are well ahead of for-profit organizations in the maturity of their PC programs. For instance, a higher incidence of respondents from non-profit organizations (60%), compared to those from for-profits (36%), report that their program has been in existence for more than six years. **Download/view at:** <http://bit.ly/2XwdpTb>

Bolstering outpatient advance care planning and palliative care in oncology: Why and how

JOURNAL OF ONCOLOGY PRACTICE | Online – 31 May 2019 – To those who say we cannot afford the time, one must answer that we cannot afford not to allocate the time to make advance directives discussion routine at adverse diagnosis or failure of therapy in advanced cancer. Every oncologist will recall with weariness and despair those patients who were treated too long, not only to their detriment but also

Cont. next page

Crossroads of Grief Project – Grieving or Bereaved Children: Literature Review (2015-2018)

CANADIAN
Virtual Hospice



Portail CANADIEN EN SOINS
palliatifs



The review covers the period 2015-2018 and supplements a literature review published by the Children & Youth Grief Network of Peel Region (of Ontario, Canada) in March 2015. The main focus is on evidence-based studies published in peer-reviewed journals, reflecting current thinking on the issues identified. A companion to this document is an ‘Overview of the Literature,’ summarizing key findings of the literature published to date and identifying gaps in research, e.g., specifically with respect to what can be described as vulnerable populations.¹ **Download/view at:** <http://bit.ly/2Z82grO>

1. Download/view an overview of the Literature Review at: <http://bit.ly/2QVwzzg>

N.B. Children & Youth Grief Network website: <http://bit.ly/2K34ghL>

to the wasting of scarce human and financial resources. When preferences are not established in advance and recorded, suffering is prolonged until after the patient becomes unable to speak for her or himself, whereupon a spouse or other responsible party sat “do everything.” If we invest more time upstream in these conversations, we will avoid some of the most distressing expenditure of effort as death approaches. The sad reality is that many of our medical oncology patients will die of their disease. Just as we do not accept failure to provide cardiopulmonary resuscitation for every viable patient who codes within our sphere of influence, no more can we say that serious illness conversation constitutes an unachievable luxury in every person with incurable cancer: **Full text:** <http://bit.ly/2wyJTQC>

Related

- *SUPPORTIVE CARE IN CANCER* | Online – 4 June 2019 – ‘**Practices and opinions of specialized palliative care physicians regarding early palliative care in oncology.**’ Although most specialized palliative care (PC) physicians [i.e., survey respondents] supported early PC in oncology, the timing of referrals was often late, and associated with characteristics of specialized PC physicians. Few supported renaming PC. Although 60% agreed that patients perceive the term “palliative care” negatively and 39% believed a name change to supportive care would encourage early referral, only 21% supported renaming the specialty. **Abstract (w. list of references):** <http://bit.ly/2QKcmMM>

Noted in Media Watch 27 May 2019 (#615, p.13):

- *JOURNAL OF SURGICAL ONCOLOGY* | Online – 18 May 2019 – ‘**Timing of palliative care: When to call for a palliative care consult.**’ Palliative care (PC), unlike hospice, can be utilized concurrently with disease-modifying or curative therapies. Some of the benefits of PC include improved quality of life, less end-of-life treatment, and decreased medical costs. Furthermore, PC can help guide treatment decisions to be in line with patients’ physical, psychological, and spiritual needs. On the basis of these benefits, the authors advocate for PC involvement early in the course of advanced malignancy and other terminal diagnoses. **Abstract:** <http://bit.ly/2VyVmtF>

Consensus building on health indicators to assess palliative care global development with an international group of experts

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 June 2019 – International consensus on indicators is necessary to standardize the global assessment of palliative care (PC) development. Twenty-four experts representing five continents and several organizations, participated in this study. Twenty-five indicators showed a high content validity and level of agreement. Policy indicators included the existence of designated staff in the national Ministry of Health, the inclusion of PC services in the basic health package and in the primary care level list of services. Education indicators focused on processes of official specialization for physicians, inclusion of teaching at the undergraduate level, and PC professorship. Use of medicines indicators consisted of opioid consumption, availability and prescription requirements. Services indicators included number and type of services for adults and children. Additional indicators for professional activity were identified. **Abstract (w. link to references):** <http://bit.ly/2KpDzmH>

Noted in Media Watch 27 May 2019 (#615, p.13):

- *THE LANCET GLOBAL HEALTH* | Online – 22 May 2019 – ‘**Global palliative care: From need to action.**’ Katherine Sleeman and colleagues report the first worldwide projection of the future global burden of serious health-related suffering.¹ The calculation followed the methods used by the Lancet Commission on Palliative Care & Pain Relief assessing global palliative care (PC) need. Combining these methods with World Health Organization’s revised global and regional projections of mortality up to 2060, the authors estimate the global burden of serious health-related suffering requiring PC by world regions and age groups for 20 health conditions. **Full text:** <http://bit.ly/2K0SxPJ>

1. ‘The escalating global burden of serious health-related suffering: Projections to 2060 by world regions, age groups, and health conditions,’ *The Lancet Global Health*, published online 22 May 2019. **Full text:** <http://bit.ly/30BUwA2>

Cont.

Noted in Media Watch 20 May 2019 (#614, p.4):

- SPAIN | Instituto Cultura y Sociedad Universidad de Navarra – Accessed 17 May 2019 – ‘**Brief manual on health indicators monitoring global palliative care development.**’ The objective of this initiative is to present a set of national-level indicators to assess the development of palliative care (PC) in different countries and regions. The resulting indicators from a consensus process with an international panel comprised of professionals in PC with extensive experience in cross-national assessment of PC development, research and advocacy. Global and international PC associations have endorsed the indicators presented in this manual. Since indicators should be adjusted to the national and regional contexts, their implementation in such studies should be preceded by discussion on the feasibility of each indicator in their specific contexts. **Download/view at:** <http://bit.ly/2Vsgt0l>

Case reports

That was then, this is now: Using palliative care principles to guide opioid prescribing

JOURNAL OF PALLIATIVE MEDICINE, 2019;22(6):612-614. Palliative care (PC) providers are committed to alleviating pain, and opioid therapy is a very important option for effective pain management. Yet we do not want to contribute to the growing problem of opioid misuse, overdose, and accidental death. So the question becomes how do we balance the important goal of reducing suffering with our equally compelling desire to act as responsible providers. Consensus-based PC principles may serve as a clinically useful guide to the decision-making process about whether or not to prescribe opioids. The approach using these familiar core principles is probably best illustrated by the following two patients – Mr. A and Mrs. B – and their complex pain management issues. **First page view:** <http://bit.ly/2KnWQVL>

Top ten tips palliative care providers should know about caring for veterans

JOURNAL OF PALLIATIVE MEDICINE, 2019;22(6):708-713. Many of America’s veterans have unique medical and psychosocial needs related to their military service. Since most medical care received by veterans occurs outside of the Department of Veterans Affairs (VA) health care system, it is imperative that all medical providers have a working understanding of the unique needs of veterans and some of the many programs and services available to veterans through the VA. This article, created by an interdisciplinary team of palliative care and hospice providers who care for veterans throughout the country, seeks to improve the comfort with which non-VA clinicians care for Veterans while increasing knowledge about programs for which veterans might qualify through the VA. **Abstract:** <http://bit.ly/2JVxBum>

Integration of a palliative care specialist in amyotrophic lateral sclerosis clinic: Observations from one center

MUSCLE & NERVE | Online – 6 June 2019 – The authors describe a one-year experience incorporating a palliative care (PC) specialist into a amyotrophic lateral sclerosis (ALS) multidisciplinary team. They describe their integration model, patient selection, and visit content. Of 500 total clinic patients, 74 (14.8%) were seen by the PC specialist in one year. Referral was most often triggered by advance care planning needs (91%). In the initial visit with the PC specialist, topics most frequently covered included goals of care (84%), anxiety/depression (35%), and medical decision making about feeding tubes (27%) or tracheostomy (31%). Symptom management comprised a relatively small number of the visits, and duration of visits was limited by patient fatigue. Patients with complex goals of care may benefit from the input of a PC specialist, and unique integration models may help to facilitate care delivery. **Abstract:** <http://bit.ly/2l18PGV>

N.B. Additional articles on PC for people living with ALS noted in 11 March 2019 issue of Media Watch, #605, p.6.



Would this article be of interest to a colleague?

Hospice philosophy in practice: Toward an authentic death

OMEGA JOURNAL OF DEATH & DYING | Online – 3 June 2019 – This article examines how hospice philosophy works in contemporary Danish hospice practice. The still sparse literature on Danish hospices indicates that hospice philosophy is influencing professional practice. In international palliative care literature, hospice philosophy is challenged for being overly normative in its ideal of the good death or on the other hand as threatened by the medical model. Drawing on the idea of hospice philosophy as providing meaning for everyday practice, this article explores how it is incorporated within the institutional order of contemporary Danish hospices. An ethnographic study was informed by participant observation and 49 interviews with professionals, patients, and families at three hospices in Denmark. The findings contribute to further understanding of the complexity of maintaining hospice philosophy in contemporary practice. Hospice practice works in an interpretive way with hospice philosophy to offer a “lived” philosophy and a means to an authentic death. **Abstract:** <http://bit.ly/2W19sgV>

REHPA

The Danish Knowledge Centre
for Rehabilitation and
Palliative Care

N.B. Additional articles on hospice and palliative care in Denmark noted in 15 October 2018 issue of Media Watch (#585, pp.9-10).

End-of-life care in Sweden

How many older adults receive drugs of questionable clinical benefit near the end of life? A cohort study

PALLIATIVE MEDICINE | Online – 7 June 2019 – The high burden of disease-oriented drugs among older adults with limited life expectancy raises important questions about the potential futility of care. A total of 58,415 decedents were included (mean age, 87.0 years). During their last 3 months of life, they received on average 8.9 different drugs. Overall, 32.0% of older adults continued and 14.0% initiated at least one drug of questionable clinical benefit (e.g., statins, calcium supplements, vitamin D, bisphosphonates, antedementia drugs). These proportions were highest among younger individuals (i.e., aged 75–84 years), among people who died from organ failure and among those with a large number of coexisting chronic conditions. A substantial share of older persons with life-limiting diseases receive drugs of questionable clinical benefit during their last months of life. Adequate training, guidance and resources are needed to rationalize and deprescribe drug treatments for older adults near the end of life. **Abstract:** <http://bit.ly/2WQgzUK>

N.B. Additional articles on drugs of questionable clinical benefit near the end of life noted in 1 April 2019 issue of Media Watch (#608, p.7).



Barry R. Ashpole

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

Evolution and conceptual foundations of non-hospice palliative care

WESTERN JOURNAL OF NURSING RESEARCH | Online – 6 June 2019 – The term non-hospice palliative care (PC) was developed to describe and differentiate PC that is delivered prior to the end of life. The purpose of this article is to better define and clarify this concept... Attributes of non-hospice PC include 1) Patient- and family-centered care; 2) Holistic care; 3) Interdisciplinary team; 4) Early intervention; 5) Quality of life-enhancing; 6) Advanced care planning; 7) Any age of the patient; 8) At any stage in illness; 9) Care coordination; 10) Concurrent curative treatment options; and, 11) Provided by primary and specialist providers. Non-hospice PC antecedents are serious illness, education, and access to services; consequences include benefits for the patient, family, provider, and health care system. Offering a clearly defined concept may allow for changes in health care to improve access to these services. **Abstract:** <http://bit.ly/2MB9LX9>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2019;191(22):E604-E613. **‘Deceased organ and tissue donation after medical assistance in dying and other conscious and competent donors: Guidance for policy.’** The authors present guidance for policy and the practice of deceased organ donation in the conscious and competent donor. Given the relatively low incidence of medical assistance in dying (MAiD) and withdrawal of life-sustaining measures (WLSM) among people who are eligible to donate organs in Canada, this practice is unlikely to substantially affect the supply of organs for potential recipients on waiting lists. The purpose of this guidance is to inform development of policies to help clinicians navigate the medical, legal and ethical challenges that arise when they respect a person’s autonomous right to request MAiD or WLSM and organ donation. **Full text:** <http://bit.ly/2XmXXIT>

N.B. See related commentary, ‘Facilitating the wishes of patients who choose both MAiD and organ donation,’ *Canadian Medical Association Journal*, 2019;191(22):E595-596. **Full text:** <http://bit.ly/3118DyZ>

Publishing Matters

Three randomized controlled trials evaluating the impact of “spin” in health news stories reporting studies of pharmacologic treatments on patients’/caregivers’ interpretation of treatment benefit

BMC MEDICINE | Online – 4 June 2019 – The authors show that spin in health news stories can affect the interpretation of study results. Research communication relies on a complex interactive ecosystem involving several stakeholders and various forces that feeds a “cycle of spin.” In an era where trustful and effective science communication is essential, there is a need to rethink and change the current ecosystem. Researchers and institutions should move from the “publish or perish” model to a model in which researchers make every effort to avoid distortion and hype. Researchers should be specifically trained to understand how citizens use the media and consequently frame their research communication to the public in a way which is truthful and relevant for the different audiences. Journalists must realize the harm that can be caused when they fail to detect spin and promote it to their readers. **Full text:** <http://bit.ly/2wGpadQ>

A journalist’s guide to writing health stories

The print and electronic media have an enormous influence on how the public views health issues. Both health policymakers and scientists recognize journalists’ effect on public understanding. Reporting health stories requires judgment about how to interpret evidence and about the implications of evidence for the public. But most journalists have little formal training in assessing the validity of evidence that bears on health issues, so inaccurate or deceptive reporting seems common.¹

1. ‘A Journalist’s Guide to Writing Health Stories,’ *American Medical Writers Association Journal*, 1999;14(1): 32-42. **Download view at:** <http://bit.ly/2Xis1Wf>

Linguistic differences between well-established and predatory journals: A keyword analysis of two journals in political science

LEARNED PUBLISHING | Online – 3 June 2019 – Predatory publishing has become a much-discussed and highly visible phenomenon over the past few years. One widespread, but hardly tested, assumption is the idea that articles published in predatory journals deviate substantially from those published in traditional journals. The authors address this assumption by utilizing corpus linguistic tools. They compare the “academic-like” nature of articles from two different journals in political science, one top-ranking and one alleged predatory. The authors’ findings indicate that there is significant linguistic variation between the two corpora along the dimensions that they test. The articles display notable differences in the types and usage of keywords in the two journals. Articles published in so-called predatory journals do not conform to linguistic norms used in higher-quality journals. These findings may demonstrate a lack of quality control in predatory journals but may also indicate a lack of awareness and use of such linguistic norms by their authors. The authors suggest there is a need for the education of authors in science writing as this may enable them to publish in higher-ranked and quality-assured outlets. **Abstract:** <http://bit.ly/2WjeXDj>



The Association of
Learned & Professional
Society Publishers

Blacklists and whitelists to tackle predatory publishing: A cross-sectional comparison and thematic analysis

mBIO | Online – 4 June 2019 – The lack of a clear conceptual foundation of predatory journals limits the meaning and applicability of current research on predatory journals. This study indicates that the blacklists and whitelists examined are helpful to inform researchers about journals that are likely fraudulent or likely legitimate. However, the lists tend to emphasize easily verifiable criteria, which are easier for journals to meet, whereas dimensions that are more difficult to assess, such as peer review, are less well covered. This study illustrates the overlap between blacklists and whitelists, indicating some journals are misclassified and others operate in a gray zone between fraud and legitimacy. Future research should aim at better defining this gray zone. The authors also encourage research to further investigate the concepts of quality, transparency, and legitimacy as well as best practices in academic publishing, specifically with regard to peer review. **Full text:** <http://bit.ly/2wCVz59>



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

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

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

South America

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

United States

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

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

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