

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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'New definition of palliative care' (p.4), presented by the International Association for Hospice & Palliative Care.

Canada

Representative sample of recent news media coverage on the issue of assisted (or facilitated) death:

St. Martha's Hospital remains firm on policy against medically-assisted dying

NOVA SCOTIA | Global-TV News (Halifax) – 9 January 2019 – A Nova Scotia Catholic congregation, thrust into a controversy about the right to die, is confident its policy will endure. The Sisters of St. Martha has an agreement with the Nova Scotia [provincial] government, forbidding medical assistance in dying, at Saint Martha's Hospital in Antigonish. "It is named in the agreement that we don't do a suicide," says Congregation leader Sister Brendalee Boisvert. Almost three years after the federal government legalized medically-assisted dying, critics say it's time for the Saint Martha's exemption to end. "The bottom line is that a faith-based institution should not be allowed to impose its' faith, its values, on the citizens of a community who may not share them," said Jocelyn Downie, a professor at the Schulich School of Law at Dalhousie University who specializes in health law. St. Martha's is far from alone. More than 100 Catholic hospitals and nursing homes across Canada also forbid medically-assisted dying, including 17 sites operated by Covenant Health in Alberta. <https://goo.gl/rN73Zc>

Specialist Publications

'Potential quality indicators for seriously ill home care clients: A cross-sectional analysis using Resident Assessment for Home Care data in Ontario (p.7), in *BMC Palliative Care*.

'Why many doctors still find it difficult to talk about dying with patients' (p.8), in *Canadian Medical Association Journal*.

'Web-based video-conferencing for rural palliative care consultation with elderly patients at home' (p.18), in *Supportive Care in Cancer*.

'Health care provider experiences of and perspectives on medical assistance in dying: A scoping review of qualitative studies' (p.19), in *Canadian Journal on Aging*.

Cont.

- QUEBEC | CTV News (Montreal) – 7 January 2019 – ‘**Quebecers with degenerative illnesses challenge medically assisted dying laws.**’ Two Quebecers suffering from incurable degenerative illnesses ... challenge federal and provincial medically assisted dying laws, arguing that the laws are too restrictive because they allow only those whose deaths are “reasonably foreseeable” to qualify irrespective of how much they are suffering. Nicole Gladu suffers from post-polio syndrome, an incurable disease with symptoms including respiratory muscle weakness, joint degeneration, muscle atrophy and skeletal deformities. Jean Truchon, the other plaintiff, has cerebral palsy. Both say their suffering is so unbearable that they wish to seek a medically assisted death in order to end their lives on their own terms. But under the federal government’s medical assistance in dying legislation, only those adults with a “grievous and irremediable medical condition” in an advanced state of irreversible decline and whose natural deaths are “reasonably foreseeable” are eligible. The Quebec law also requires that applicants be “at the end of life.” <https://goo.gl/MBZijD>
- ALBERTA | *The Calgary Herald* – 5 January 2019 – ‘**Families to be consulted to improve Alberta’s assisted death program.**’ As of the end of November, 278 Alberta patients had taken advantage of the medical assistance in dying (MAiD) program in 2018, eclipsing the combined total from all of 2017 and the seven months of the previous year after federal legislation removed the need for a court order to undergo physician-assisted death. Since June 2016, some 546 Albertans have gone through the process. A further 132 were denied because they didn’t meet federal criteria, the most common being patients who’ve lost the mental capacity to consent to the procedure. Dr. James Silvius, who oversees the Alberta program, said the process continues to evolve thanks to lessons learned over 2½ years, leading Alberta Health Services to begin surveying family members about their experiences with the program to help smooth out some of the rougher edges. One of the more common concerns fielded by loved ones in the early days of the program was the practice of physicians preparing the medications that would be administered to patients in their homes, a lengthy process that took a toll on families standing by for the end. <https://goo.gl/6kPycW>

U.S.A.

What’s the last song you want to hear before you die?

THE WASHINGTON POST | Online – 11 January 2019 – Listening to familiar musical passages can prompt significant emotional responses, causing the release of neurotransmitters such as dopamine. In particular, they are released in an ancient segment of our brains, known as the striatum, which is associated with emotional responses to rewarding inputs such as food, sex, drugs and ... rock-and-roll. What happens to the brain in our dying moments? The shutting-down process is not as straightforward as you might imagine. Most of the research on the topic has been done with rodents, so we may not be able to extrapolate too much. But dying rats experience heightened activity in their frontal cortical areas, when the oxygen and glucose have been taken away and there is a huge influx of calcium into their brain cells. Our ability to have conscious thought and experience depends on the strength of the connections between the frontal areas of the brain, associated with mental abilities, and those nearer the back of the brain that process sensory information. These connections, in dying rats, actually strengthened by five to eight times after cardiac arrest, compared with

waking moments. Such a surge in the human brain may explain why some people who have near-death experiences report heightened sensory information. Those who are dying may also be able to process auditory information better than is generally assumed. It is entirely feasible that, in our dying moments, we are more aware of what is happening around us than previously believed. <https://goo.gl/kAVBko>

Specialist Publications

‘**Trends in hospice quality oversight and key challenges to making it more effective, 2006-2015**’ (p.13), in *Journal of Palliative Medicine*.

‘**Statewide differences in personality associated with geographic disparities in access to palliative care: Findings on openness**’ (p.14), in *Journal of Palliative Medicine*.

‘**Racial differences in health care transitions and hospice use at the end of life**’ (p.14), in *Journal of Palliative Medicine*.

Florida hospice doctors seek exemption from drug database

FLORIDA | WTXL-TV (Tallahassee) – 9 January 2019 – Less than a year after the Florida Legislature passed a sweeping bill that requires physicians to check a statewide database before ordering opioids for patients, lawmakers are being asked to consider an exemption for doctors who care for dying people. It's not because the requirement is burdensome for the doctors, said Stephen Leedy, a board-certified hospice and palliative care (PC) physician. Instead, it's because checking the prescription-drug database each time controlled substances are ordered for dying people leads to delays, causing the patients to unnecessarily suffer at the end of life, he said. The requirement for physicians to check the database is aimed, at least in part, at preventing drug abusers from "doctor shopping" to improperly get controlled substances. "We feel hospice and PC providers do not contribute to the diversion problem within the state of Florida, and hospice patients do not either," Leedy told members of the Senate Health Policy Committee. Leedy said Florida had 137,000 hospice patients last year. On average, they were in hospice for three weeks before dying. "During those three weeks, these patients were not out there 'doctor shopping.' They were not out there looking for opioids in the streets. They were mainly bed-bound and in pain, short of breath, being managed by hospice providers," he said. <https://goo.gl/TYTsA9>

How helping patients get good care at home helps rural hospitals survive

KAISER HEALTH NEWS | Online – 8 January 2019 – Rural hospitals close when they don't have enough paying patients to care for, but they're also dinged when the same patients show up over and over again. That puts outlying medical facilities in the precarious position of needing to avoid repeat customers. Hospitals used to run on a so-called fee-for-service model with virtually no limit to how many times they could see a patient. But, under pressure from private and government insurance programs, that model is transitioning to one in which hospitals are rewarded for safety and efficiency – which often results in a patient spending less time in the hospital. Under the Affordable Care Act, Medicare began to ding hospitals if too many patients are readmitted to any hospital within 30 days of discharge. The measure is broadly unpopular with the hospital industry,

since so much falls outside a hospital's control. Medicare has even walked even back the rules for safety-net facilities, which tend to treat a sicker population. The penalty is meant to encourage hospitals to get it right the first time. <https://goo.gl/SyH7h1>

Extracts from *Kaiser Health News* article

Advance directives are on the agenda for next time – another way to keep people near the end of life from becoming ER regulars.

The group brainstormed how to generate the same kind of acceptance for hospice care, which – as one doctor in the meeting put it – some families view as "assisted suicide."

Noted in Media Watch 21 May 2018 (#564, p.2):

- MINNESOTA | United Health Foundation – 17 May 2018 – '**New report on senior health shows rural health disparities persist...**' A new report benchmarking the health of seniors in America finds poorer health outcomes for rural senior citizens compared with their urban and suburban peers. An analysis within the report also highlights the risk of social isolation and its association with poor health for seniors. The report provides the latest check-up on the health and well-being of the nation's seniors. Using 34 measures of senior health, the report highlights successes and challenges this population faces on a national and state-by-state basis. **Download/view report (see pp.79-80) at:** <https://goo.gl/5DDW1F>

N.B. Selected articles on the provision and delivery of hospice and palliative care services in rural America noted in 23 April 2018 issue of Media Watch (#560, p.12).



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These states are most concerned about end-of-life issues

HOME HEALTH CARE NEWS | Online – 6 January 2019 – While roughly 90% of Americans agree that discussing end-of-life (EoL) care with their loved ones is important, only 27% actually follow through with conversations focused on planning, according to research from public engagement initiative The Conversation Project.¹ Although many have ramped up community outreach efforts, that aversion to thinking about death has been a roadblock for hospice providers in some parts of the country. A new study by Dallas-based life insurance technology company Bestow Inc. has identified several states where EoL is on people's minds, however.² Overall, Wisconsin is the state most concerned about EoL issues, with New York as a close second, according to the Bestow study. New Hampshire, South Dakota and Ohio make up the rest of the top five, in order. The states least concerned about EoL issues: Nevada, California, Wyoming, Utah and Alaska. <https://goo.gl/Vaxxdm>

1. '5 End-of-life care stats everyone should know,' The Conversation Project, May 2016. **Downloaded/viewed at:** <https://goo.gl/MvabdC>
2. 'What states are most concerned about end-of-life issues,' Bestow Inc., December 2018. **Downloaded/viewed at:** <https://goo.gl/zLeAwn>

International

New definition of palliative care

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE | Online – Accessed 8 January 2019 – In December 2018, the Association presented a global, consensus-based definition of palliative care (PC) resulting from a year-long, three-phase process involving hundreds of experts and everyday practitioners representing 88 countries. One of the challenges of PC implementation has been a lack of consensus on what PC is, when it should be offered, to whom, and by whom. Furthermore, the terms “palliative care” and “hospice care” have been used interchangeably, but are interpreted differently. A 2002 definition by the World Health Organization (WHO) limits PC to a service that can be offered to relieve problems associated with life-threatening illnesses.¹ Following the recommendation of *The Lancet* Commission on PC and pain relief,² and as an organization in official relations with the WHO, the Association designed, developed, and implemented a project to revise and adopt a new PC definition. The objective was to find consensus on a definition that focuses on the relief of suffering, and is also

timely and applicable to all patients regardless of diagnosis, prognosis, geographic location, point of care, or income level. **Download/view at:** <https://goo.gl/PUcgkS>

Specialist Publications

'Cancer patients hospitalised in the last week of life risk insufficient care quality: A population-based study from the Swedish Register of Palliative Care' (p.5), in *Acta Oncologica*.

'Monitoring the Italian home palliative care services' (p.9), in *Healthcare*.

'Understanding the barriers to introducing early palliative care for patients with advanced cancer: A qualitative study' (p.12), in *Journal of Palliative Medicine*.

'Global palliative care and cross-national comparison: How is palliative care development assessed?' (p.13), in *Journal of Palliative Medicine*.

1. 'Definition of Palliative Care,' WHO, 2002. **Download/view at:** <https://goo.gl/UPvF38>
2. 'Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,' *The Lancet*, published online 12 October 2017. [Noted in 16 October 2017 issue of *Media Watch* (#534, p.14)] **Full text:** <https://goo.gl/i7r9M1>

Cont.

Noted in Media Watch 12 March 2018 (#554, p.10):

- *THE LANCET GLOBAL HEALTH*, 2018;6(Supplement 1):S5-S6. ‘**The Lancet Commission on Palliative Care & Pain Relief: Findings, recommendations, and future directions.**’ About 25.5 million of 56.2 million people who died in 2015 experienced serious health-related suffering, and another 35.5 million experienced serious health-related suffering due to life-threatening and life-limiting conditions. A disproportionate number (more than 80%) of these 61 million individuals live in low-income and middle-income countries with severely limited access to any palliative care (PC), even oral morphine for pain relief. Furthermore, nearly 2.5 million children worldwide die in need of PC and pain relief, and more than 90% of paediatric deaths associated with serious health-related suffering are avoidable. These are a few of the most salient findings of the report of the *Lancet* Commission on Global Access to Palliative Care & Pain Relief. **Full text:** <https://goo.gl/PhbGZw>

Top 10 countries most at risk of humanitarian disaster in 2019

ALJAZEERA | Online – 6 January 2019 – The International Rescue Committee (IRC) has named the countries most at risk of being hit by humanitarian catastrophe next year, with Yemen, the Democratic Republic of Congo and South Sudan topping the top 10 list. As wars, famines and other disasters loom over several countries, 2019 is set to be another arduous year for millions of people around the world. The next seven at-risk countries identified by the IRC's emergency response experts are Afghanistan, Venezuela, the Central African Republic, Syria, Nigeria, Ethiopia and Somalia. The risks are both human (armed conflicts or economic collapse) as well as natural (droughts, floods and other climate-related events). Internal or external displacement is the defining trend in the IRC list. Around 40 million people have been displaced across the world, with the top 10 countries accounting for over half – or nearly 22 million – of those displacements. <https://goo.gl/bxjuVW>



N.B. Selected article on integrating palliative care and symptom relief into responses to humanitarian emergencies and crises noted in 10 December 2018 issue of Media Watch (#593, p.11).

Specialist Publications

Cancer patients hospitalised in the last week of life risk insufficient care quality: A population-based study from the Swedish Register of Palliative Care

ACTA ONCOLOGICA | Online – 11 January 2019 – Important aspects of end-of-life (EoL) care that emerges when interviewing terminally ill cancer patients include the importance of being free from pain and other distressing symptoms and to be well supported by their health-care team. Clearly, many patients want to be involved in decisions about their EoL phase. Studies further indicate that a majority of them wish to be cared for at home in their final days. Nevertheless, some patients instead prefer to die in hospice, hospital or a nursing home. In Sweden, one in four cancer patients spends the last week of life in hospital. To what extent a “good death,” including adequate symptom control and comfort for the patient as well as information and support to the family, can be equally achieved in a hospital compared to a dedicated palliative care (PC) setting is insufficiently studied. Using a population-based nationwide ap-

proach, The authors detected systematic differences in EoL care quality among Swedish cancer patients in their last week of life in relation to place of death. In particular, their findings stress a need for improvement of the PC process for hospitalised patients in the terminal phase. Further research is needed to identify what underlying mechanisms contribute to these differences as well as to identify strategies to ensure equality and competence in EoL care irrespective of place of death. **Full text:** <https://goo.gl/UtAAjV>

Publishing Matters

‘**Plagiarism and predatory journals: A threat to scientific integrity**’ (p.19), in *Anales de Pediatría*.

‘**Scientific spam**’ (p.20), in *Ugeskr Laeger*.

Trauma surgeon and palliative care physician attitudes regarding goals-of-care delineation for injured geriatric patients

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 January 2019 – The value of defining goals of care (GoC) for geriatric patients is well known to the palliative care (PC) community but is a newer concept for many trauma surgeons. PC specialists and trauma surgeons were surveyed to elicit the specialties' attitudes regarding: 1) Importance of GoC conversations for injured seniors; 2) Confidence in their own specialty's ability to conduct these conversations; and, 3) Confidence in the ability of the other specialty to do so. Respondents included 118 trauma surgeons (8.8%) and 244 PC specialists (5.7%). Palliative physicians rated being more familiar with GoC, were more likely to report high-quality training in performing conversations, believed more palliative specialists were needed in intensive care units, and had more interest in conducting conversations relative to trauma surgeons. Both groups believed themselves to perform GoC discussions better than the other specialty perceived them to do so and favored their own specialty leading team discussions. **Abstract:** <https://goo.gl/tPyJPR>

Healthcare professionals' moral distress in adult palliative care: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 11 January 2019 – Palliative care (PC) providers may be exposed to numerous detrimental psychological and existential challenges. Ethical issues in the healthcare arena are subject to continual debate, being fuelled with ongoing medical, technological and legal advancements. This work aims to systematically review studies addressing the moral distress experienced by healthcare professionals who provide adult PC. The initial search identified 248 papers and 10 of them were considered eligible. Four main areas were identified: 1) Personal factors; 2) Patients and caregivers; 3) Colleagues and superiors; and, 4) Environment and organisation. Managing emotions of self and others, witnessing suffering and disability, caring for highly demanding patients and caregivers, as well as poor communication were identified as distressing. Moreover, the relationship with colleagues and superiors, and organisational constraints often led to actions which contravened personal values invoking moral distress. The authors also summarise some supportive and preventive recommendations including self-empowerment, communication improvement, management of emotions and specific educational programmes for PC providers. A holistic model of moral distress in adult PC – integrating emotional, cognitive, behavioural and organisational factors – is also proposed. **Abstract:** <https://goo.gl/VmB4DR>

End-of-life care in France

Medical staff opposition to a deep and continuous palliative sedation request under Claeys-Leonetti law

BMC PALLIATIVE CARE | Online – 10 January 2019 – The Claeys-Leonetti law created the right to deep and continuous sedation (CS). An opinion survey conducted among patients treated in different palliative care (PC) institutions showed that up to 83% PC patients were in favor of the right to deep and CS. Nevertheless, 53% of patients reported opposition to legalized euthanasia. Despite these different opinions between palliative sedation (PS) and euthanasia, patient's expectation regarding PS can be ambivalent with properly so called euthanasia or assisted suicide... This ambivalent perception was part of the controversy surrounding the parliamentary debate. Some regard the practice of PS as proper medical care, whereas others see CS as slow, disguised, and socially acceptable form of euthanasia. Moreover, the authors' clinical case raises the question of intention in deep and CS until death at the patient's request. This problem of intention, already put into work for sedation, has been partly resolved by the principle of double effect. This case report supports that deep and CS under Claeys-Leonetti law need to meet specific criteria defined by the law. Criteria for application of PS should be clearly identified and documented in the medical files as a safeguard against inappropriate practice. Prudent practice involve standardized decision-making model for medical team guidance. Implementation of a medical ethics decision-making model is quite similar to that of medical guidelines. **Full text:** <https://goo.gl/DMXr5w>

Cont.

Noted in Media Watch 19 March 2018 (#555, p.12):

- *STATUTE LAW REVIEW* | Online – 14 March 2018 – ‘**Patient’s orders: Patient’s rights and the doctor’s obligations under the Claeys-Leonetti Law of 2016 in France.**’ France enacted the Claeys-Leonetti law in 2016, becoming one of the first countries to legalize terminal sedation as a medico-legal practice in the world. The focus of this short paper is to highlight the limitations imposed by Claeys-Leonetti on the doctor to fulfil his or her ethical duties under the Hippocratic Oath to act “for the benefit of my patient,” but to act only according to the “wishes of the patient,” to eliminate all forms of pain and suffering. A legislative commentary will be provided for the first five pertinent articles followed by proposals for reform. **Full text:** <https://goo.gl/fzDzf5>

N.B. Additional articles on PS noted in this issue of Media Watch.

Potential quality indicators for seriously ill home care clients: A cross-sectional analysis using Resident Assessment for Home Care data in Ontario

BMC PALLIATIVE CARE | Online – 9 January 2019 – 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 QIs 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. The potential quality indicators (QIs), based on the Resident Assessment Instrument for Home Care (RAI-HC), can serve as decision-support tools during the process of continuous quality improvement, while organizations attempt to understand the current quality issues they face and how interventions can influence the QI rates over time. Home care clients in Ontario who are seriously ill are experiencing high rates of negative health outcomes, many amenable to change. The RAI-HC can be a useful tool in identify these clients in order to better understand their needs and abilities. The RAI-HC can also be used to flag potential quality issues at the organizational level. **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>

Are care staff equipped for end-of-life communication? A cross-sectional study in long-term care facilities to identify determinants of self-efficacy

BMC PALLIATIVE CARE | Online – 8 January 2019 – This study provides a good starting point for improving end-of-life (EoL) conversations in long-term care facilities by providing evidence about factors that could improve care staff’s self-efficacy. As higher self-efficacy is associated with an increased likelihood of performing a certain procedure, nursing education programs should pay more attention to palliative care and EoL conversations in their curriculum and use more experiential/bedside learning methods to promote successful experience with this in an early stage of working life. Moreover, clear agreements about who should take responsibility for initiating EoL conversations should be made, as the absence of agreements might hamper EoL conversations. **Full text:** <https://goo.gl/CqraC4>

Related

- *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 health care 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 (LTC) environment and non-registered, direct care workers. This research examined the moral concerns of personal support workers who provide direct care to residents. Two main moral dilemmas were ensuring that residents don’t die alone, and providing the appropriate care based on residents’ wishes. Their organizational constraints coalesced around policies, hierarchy, time, and balancing residents’ needs. **Abstract (via PubMed):** <https://goo.gl/41Ggzj>

Why many doctors still find it difficult to talk about dying with patients

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2019;191(1):E22-E23. Death is the ultimate inconvenient truth, its inevitability a conversation that far too many doctors still go out of their way to avoid, according to a recent report by Britain's Royal College of Physicians...¹ The report looks at why doctors and other health care professionals find it so difficult to talk about dying to patients who are frail or terminally ill. Everyone realizes that early and honest conversations allow both doctors and patients to better explore the choices around their future care. So why isn't it happening as often as it should? The report cites three barriers identified by doctors. Some struggle with the limitations of medicine, perceiving death as failure, while others feel ill-equipped to initiate the conversation. The final barrier was of a more practical nature: confusion over which of the patient's caregivers should take the lead in opening a dialogue.

Full text: <https://goo.gl/6azMjq>

1. 'Talking about dying: How to begin honest conversations about what lies ahead,' Royal College of Physicians, October 2018. [Noted in 22 October 2018 issue of Media Watch (#586, p.3)] **Download/view at:** <https://goo.gl/4bh27r>

Related

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 10 January 2019 – '**Communication in cancer: Its impact on the experience of cancer care communicating with the angry patient and the patient in denial.**' In a review of recent literature, clinicians had improved perceived self-efficacy in responding to patient anger after completing anger management training, with a focus on reframing anger as a normative response to unmet needs. The detrimental effects of avoiding communication about cancer and dying in patients and families include increased stress and emotional burden, patient depression and anxiety and regret in bereaved family members. **Abstract:** <https://goo.gl/Thzqae>

What do displays of empathy do in palliative care consultations?

DISCOURSE STUDIES | Online – 7 January 2019 – Empathy is an important way for doctors to demonstrate their understanding of patients' subjective experiences. This research considers the role of empathy in 37 doctor-patient palliative or end-of-life care consultations recorded in a hospice. Specifically, it focuses on four contexts in which there is a disparity between patients' displayed experience of their illness and the doctor's biomedical, expertise-driven perspective on their illness. These include cases in which the patient is sceptical of the medical perspective, cases in which the patient's expectations exceed what can realistically be provided and cases in which patients have an overly pessimistic view of their condition. The analysis shows how doctors can use empathic statements to display that they are attentive to the patient's subjective experience even when the task at hand is, ostensibly, an expertise-driven, biomedical one. It thus demonstrates that empathy is of importance throughout palliative care consultations, even in those phases which might seem biomedical or task-driven. **Abstract:** <https://goo.gl/32X3Mb>

Noted in Media Watch 19 March 2018 (#555, p.6):

- U.K. (England) | BBC News – 12 March 2018 – '**Genes have a role in empathy, study says.**' It helps us to make close connections with people, and influences how we behave in a range of situations. Now scientists say empathy is not just something we develop through our upbringing and life experiences – it is also partly inherited. A study of 46,000 people found evidence for the first time that genes have a role in how empathetic we are.¹ And it also found that women are generally more empathetic than men. <https://goo.gl/6Ntoz9>

1. 'Genome-wide analyses of self-reported empathy...,' *Translational Psychiatry*, published online 12 March 2018. **Full text:** <https://goo.gl/mY1Ekj>

Palliative design meets palliative medicine: A strategic approach to the design, construction, and operation of healthcare facilities to improve quality of life and reduce suffering for patients, families, and caregivers

HEALTH ENVIRONMENTS RESEARCH & DESIGN | Online – 11 January 2019 – A built environment designed to be appropriate for palliative care can make a profound difference for people with life-limiting illnesses. The built environment affects a patient's quality of life, the management of physical and psychological symptoms, and the quality of social interactions with loved ones and caregivers. This article is informed by the emerging trends in the research and practice in the disciplines of architecture, design, medicine, and nursing. It is intended to provide a definition of palliative design and invite discussion of its potential impact on patients, families, and caregivers. **Abstract:** <https://goo.gl/eSqYVL>

N.B. Selected articles on the relationship between the architecture of health care facilities and the quality of end-of-life care noted in 16 July 2018 issue of *Media Watch* (#572, pp.1-2).

A “separation of worlds”: The support and social networks of family carers of people with dementia at the end of life, and the possible role of the internet

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 8 January 2019 – Caring for someone with dementia is one of the most challenging caring roles in today's society. A new study has explored the support and social networks of family carers of people with dementia towards the end of life and the role of the internet in supporting them. In interviews with 20 current and former family carers aged 65 and over in England, carers described a separation of two worlds: their internal caring world and the outside world of society, with varying networks of support. Carers discussed experiencing a spectrum of losses but also a process of reconstruction of life as a carer. The internet helped to provide support, including options to develop new relationships and networks. The internet alone was not enough, however, and human interaction was still needed. **Summary:** <https://goo.gl/Fk7kBB>

Monitoring the Italian home palliative care services

HEALTHCARE | Online – 2 January 2019 – Despite its limitations (i.e., voluntary participation) and the reliability of the data provided by the registered home palliative care services (HPCS), this study demonstrates a good degree of HPCS participation at a national level. In 2013 nearly 40,000 patients were assisted at home with palliative care (PC) provided by registered HPCS. 84.4% of deceased cancer patients had been enrolled in HPCS within 3 days from referral (a national regulatory standard), yet a significant proportion of patients were enrolled beyond that 3-day term. The deceased cancer patients had been visited by nurses approximately 2.2 times per week and approximately 1.3 times per week by physicians. For deceased patients, the mean intensity of care coefficient is consistent with the Italian regulatory standards and ... the mean duration of care (61 days) corresponds to the one reported by other PC observers, with a value included between the one recorded by the Australian Patient Care Outcomes Collaboration (mean 38.3 days) and by the English Minimum Data Set for Specialist Palliative Care (about 100 days). With regard to the main outcome for deceased patients, a large proportion of assisted patients died at home, (respectively nearly 75% and 80% for cancer and non-cancer patients) whereas a lower percentage of deaths occurred at the hospital (around 10%). **Full text:** <https://goo.gl/KW6KrZ>

N.B. Patient Care Outcomes Collaboration and Minimum Data Set for Specialist Palliative Care reports can be downloaded/viewed, respectively, at: <https://goo.gl/L3oit3> and <https://goo.gl/Dbvzty>.

Noted in *Media Watch* 26 March 2018 (#556, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 20 March 2018 – ‘**The “ARIANNA” Project: An observational study on a model of early identification of patients with palliative care needs through the integration between primary care and Italian home palliative care units.**’ In this multicenter prospective observational study, 937 patients, out of a pool of 139,071, were identified by GPs as having a low life expectancy and palliative care (PC) needs. The GPs sent 433 patients to the home PC units for multidimensional assessment, and 328 (75.8%) were placed in the care of both settings (basic or specialist). For all patients included in the study, both oncological and non-oncological patients, there was a high rate of death at home, around 70%. **Abstract:** <https://goo.gl/Le2Pr9>

A reflective case study in family medicine advance care planning conversations

JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE, 2019;32(1):108-114. Advance care planning conversations in the office setting are often challenging. Patients frequently avoid them, and surrogates are stressed when asked to participate. Many clinicians struggle with how to raise the subject, and, when they do, continue to struggle with how to discuss it in a supportive and meaningful, yet still practical and time-efficient way. The authors' experience, however, is that most physicians and patients support future health care planning, even if they do find it difficult. They also strongly believe that the best clinician to discuss an individual's goals-of-care is that person's family physician – the medical professional whose relationship with the patient addresses the fullness of the patient's bio-psycho-social situation. The integrative approach the authors present here is an application of one they have previously described as a "family medicine ethics." Such an approach begins with developing an ethos of asking the question: "What, all things considered, should happen in this situation?" at every clinical encounter. Answering this question involves 4 broad steps: 1) Identifying situational issues; 2) Identifying involved stakeholders; 3) Gathering subjective and objective data; and, 4) Analyzing issues and data to direct action and guide behavior. **Full text:** <https://goo.gl/ppASx1>



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- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 9 January 2019 – **'Things to consider when completing an advance directive.'** Questions from patients about pain conditions and analgesic pharmacotherapy and responses from authors are presented to help educate patients and make them more effective self-advocates. In response to a question about advance directives for a patient experiencing chronic pain, the authors discuss the importance of having legal documents in place. **Abstract:** <https://goo.gl/p3rva8>
- *PATIENT EDUCATION & COUNSELING* | Online – 11 January 2019 – **'An integrative review of stakeholder views on advance care directives: Barriers and facilitators to initiation, documentation, storage, and implementation.'** There are several barriers and facilitators to the initiation of advance care planning (ACP) discussions, documentation and implementation of advance care directives, and little research exploring the views of legal professionals on the development, storage, or use of ACP documents. **Abstract:** <https://goo.gl/yBP7aT>

Theories of loss and grief experienced by the patient, family, and healthcare professional: A personal account of a critical event

JOURNAL OF CANCER EDUCATION | Online – 3 January 2019 – When a patient is diagnosed with cancer, a number of losses and grief processes occur. Theories and models of loss, grief, and mourning are explored for the patient, her family member, and the medical treatment team, through a personal reflection when treating a patient undergoing a course of radiation treatment in a large cancer center. Reflection on this event can be used to guide health care facilities to assess and develop support systems for patients, caregivers, and health care professionals to cope with loss and grief processes in a healthy and meaningful way. **Abstract (w. list of references):** <https://goo.gl/6KRq9Q>

Related

- *MORTALITY* | Online – 11 January 2019 – **'Death, loved ones and relationality: Continuities and discontinuities.'** This article looks at the ways in which the dead continue to be embedded in the lives of the living and contribute to the sense of self; it also considers the role of lived experiences, such as encounters with the dead, in creating and maintaining a sense of ongoing connectedness. However, relationships sometimes involve complex and even damaging histories, and this may affect a person's willingness to continue the bond beyond the grave. **Abstract:** <https://goo.gl/n2pevV>



Closing the Gap Between Knowledge & Technology
<http://goo.gl/OTpc8I>

Spiritual uncertainty among hospice providers – “there were tensions”

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(1):90-95. How providers of end-of-life (EoL) care perceive spirituality both within themselves and for others can directly impact their ability to provide spiritual care to patients and families. Uncertainty about spirituality can contribute to the awkwardness of spiritual care. Spiritual uncertainty includes the questions, worries, and doubts people have about the meaning, beliefs, connections, self-transcendence, and value that comprise spirituality. This article reports qualitative findings from a mixed-methods study that sought to understand spiritual uncertainty among hospice providers. Data were collected from 28 hospice team members (nurses, physicians, social workers, and expressive therapist) using focus groups, reflective journals, and one-on-one interviews. An overarching theme emerged that described the tensions perceived by providers caring for hospice patients. Those tensions were further categorized as being interpersonal, intrapersonal, and transpersonal in nature. The identification of tension as a source of strain for providers delivering spiritual care is necessary to the development of future interventions that can assist providers and patients navigating EoL spirituality. **Abstract:** <https://goo.gl/zD374w>

Noted in Media Watch 22 October 2018 (#586, p.5):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 October 2018 – ‘**Development of a tool to identify and assess psychosocial and spiritual needs in end-of-life patients...**’ The Psychosocial & Spiritual Needs Evaluation scale was developed through a 7-stage process: 1) Literature review; 2) Expert panel establishment; 3) Discussion and agreement on the most relevant dimensions of psychosocial care; 4) Description of key indicators and consensus-based questions to evaluate such dimensions; 5) Assessment of the scale by palliative care professionals; 6) Evaluation by patients; and, 7) Analysis of scale’s psychometrics properties. **Abstract (w. list of references):** <https://goo.gl/ETVDQh>

Case study in cross-cultural healthcare and ethics

Who decides what is in the child’s “best interest”?

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(1):8-13. Healthcare in the U.S. is increasingly delivered in cross-cultural contexts. Empathy, mutual regard, respect, and compassionate communication are necessary to achieve the highest standard of care for each individual. Moral and ethical perspectives on life and death, health, and healthcare are not universal but rather have their origins within culture and societal norms. In a cross-cultural context, “the right decision” may be seen differently depending on an individual’s cultural background, discipline, and type of education. This pediatric case study is intended to stimulate conversation on the need for culturally sensitive healthcare decision making and the shortcomings of a “one-size-fits-all” approach to bioethics in our increasingly interconnected world. **Abstract:** <https://goo.gl/mT8TwB>

Noted in Media Watch 8 October 2018 (#584, p.15):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 October 2018 – ‘**Top ten tips palliative care clinicians should know about caring for children.**’ Given the limited number of pediatric-specific palliative care (PC) programs, PC providers of all disciplines may be called on to care for infants, children, and adolescents with serious illness. This article provides a review of the unique components of pediatric PC, including key roles within an interdisciplinary team, pediatric developmental considerations, use of medical technology and complexities of symptom management in children with serious illness, hospice utilization, as well as pointers for discussions with families regarding a patient’s quality of life and goals of care. **Abstract:** <https://goo.gl/AsU6q6>

N.B. Selected articles on pediatric PC noted in this issue of Media Watch.

Hearing loss: Effect on hospice and palliative care through the eyes of practitioners

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 January 2019 – Discussions regarding values and goals of care (GoC) are central to providing quality palliative care. An inability to hear during these sensitive discussions may significantly impair the quality of care provided yet hearing loss (HL) is not formally addressed in these settings nor in programs designed to assist practitioners gain advanced communication skills. Of 510 respondents [to an online survey], 464 (91%) reported HL had some or great impact on the quality of care provided, 449 (88%) noted encountering a situation where HL impaired communication with an older adult, and 99 of these participants (22%) provided a specific example. The overarching theme was “diagnostic and treatment uncertainty.” Non-mutually exclusive categories underpinning this theme included: unable to get needed information, misinterpreting level of understanding, patient misunderstanding of instructions, and GoC errors. HL impacts the quality of care provided to persons with serious illness by disrupting the identification, assessment, and treatment of the physical, psychosocial and spiritual symptoms an individual is experiencing. HL should be formally addressed in programs designed to develop skills in conducting sensitive conversations. Practitioners should screen for HL, use practices that facilitate comprehension, and use assistive listening devices as needed. **Abstract (inc. link to references):** <https://goo.gl/189cVF>

Noted in Media Watch 22 January 2018 (#547, p.10):

- *BRITISH MEDICAL JOURNAL* | Online – 18 January 2018 – ‘**Tackling hearing loss to improve the care of older adults.**’ Clinical care is often delivered in settings where people with hearing loss struggle to understand speech. Communication is key for healthcare quality and safety, so people with hearing loss are at risk of receiving poor care. Simple steps can improve communication in clinical encounters. Changes in practice environments, processes, and policies could substantially improve the quality of medical care. But first, we need greater awareness. **Abstract:** <https://goo.gl/yWdDS8>

N.B. Additional articles on the implications of hearing loss in the context of elder and end-of-life care are noted in 28 August 2017 issue of Media Watch (#527, p.5).

Understanding the barriers to introducing early palliative care for patients with advanced cancer: A qualitative study

JOURNAL OF PALLIATIVE MEDICINE | Online – 11 January 2019 – The findings of this study suggest that referral to palliative care (PC) specialists shortly after the diagnosis of advanced cancer increases the terminological barriers, induces avoidance patterns, and makes early disclosure of poor prognosis harder for oncologists. This situation is attributable to the widespread idea that PC means terminal care. In addition, the fact that the “early palliative care” (EPC) concept is poorly understood increases the confusion between EPC and supportive care. Defining the EPC concept more clearly and explaining to health professionals and patients what EPC consists of and what role it is intended to play, and the potential benefits of PC services could help to overcome the wording barriers rooted in the traditional picture of PC. **Abstract:** <https://goo.gl/Z8LG9E>

Noted in Media Watch 10 December 2018 (#593, p.15):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 6 December 2018 – ‘**Evidence of palliative care stigma: The role of negative stereotypes in preventing willingness to use palliative care.**’ Although palliative care (PC) is critical in the management of symptoms, pain and transitions to end-of-life care among those facing serious or chronic illness, it is often underused, which may be due to stigma associated with PC representing giving up fighting one’s illness. **Abstract (w. list of references):** <https://goo.gl/59E3F2>

N.B. Selected articles on terminology in the context of living with a life-threatening or life-limiting illness and end-of-life care noted in 10 September 2018 issue of Media Watch (#580, pp.7-8).

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

Trends in hospice quality oversight and key challenges to making it more effective, 2006-2015

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 January 2019 – Given the limited ability of hospice patients to assess, monitor and respond to sub-standard care, quality oversight has an important role to play in the hospice sector. The Improving Medicare Post-Acute Care Transformation (IMPACT) Act (2014) required that agencies be recertified at least every three years, but it did not otherwise alter hospice quality oversight. The authors illuminate the current hospice quality oversight process and discuss its role alongside other government monitoring and public reporting efforts. The proportion of privately accredited hospice agencies increased from 15% to 39%, a trend driven largely by its increased use among for-profit agencies. The combined rate of deficiencies per agency increased 35% over the past decade, with issues around care planning, aide and homemaker services, and clinical assessment featured most prominently. Nearly half (45%) of all surveys resulted in deficiency citations; however, less than one-in-four hospice agencies were surveyed in a given year. Over the past decade, 28 agencies were terminated from the Medicare program; most of these agencies were unaccredited and operated on a for-profit basis. The IMPACT Act addressed one of the biggest shortcomings in hospice oversight. The authors findings highlight additional reforms that could be considered. First, reporting inspection results from private and public recertification surveys could promote greater transparency and accountability. Second, making a wider range of intermediate sanctions available to oversight agencies could enhance enforcement efforts and, ideally, incentivize agencies to improve quality of care. **Abstract:** <https://goo.gl/YZDUjo>

Global palliative care and cross-national comparison: How is palliative care development assessed?

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 January 2019 – Indicators assessing national-level palliative care (PC) development used for cross-national comparison depict progress on this field. There is current interest on its inclusion in global monitoring frameworks. Fifty-four studies were included in this systematic review. Development was evaluated using 480 different formulations of 165 indicators, 38 were highly reported. Thirty-two fell into proposed dimensions, 11 for use of medicines, 9 for policy, 7 for services, and 5 for education. Six into complementary dimensions: research, professional activity, and international cooperation. Six were the most frequently used indicators: 1) Number of PC services per population (40 reports); 2) Existence of PC national plan, strategy, or program (25); 3) Existence of palliative medicine specialization (22); 4) Availability and allocation of funds for PC (13); 5) Medical schools, including PC, in undergraduate curricula (13); and, 6) Total use of opioids-morphine equivalents (11). There is a clear pattern for national-level PC development evaluation repeatedly using a small number of indicators. Indicators addressing generalistic provision, integration into health systems, and specific fields such as pediatric lack. **Abstract:** <https://goo.gl/Fe6uqC>



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Noted in Media Watch 2 July 2018 (#570, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 25 June 2018 – ‘**Re-framing global palliative care advocacy for the sustainable development goal era: A qualitative study of the views of international palliative care experts.**’ The World Health Assembly Palliative Care Resolution in 2014 and the inclusion of palliative care (PC) within the sustainable development goals raised optimism that PC would no longer be a peripheral aspect of global health. However, no funding, accountability measures or indicators for PC development accompanied these policy developments. This risks health actors continuing to prioritize the attainment of better known, target-driven aspects of health-care. 16 PC experts were interviewed for their epistemic expertise. **Abstract:** <https://goo.gl/qYqf13>



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.20.

Statewide differences in personality associated with geographic disparities in access to palliative care: Findings on openness

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 January 2019 – Geographic disparities in access to palliative care (PC) cause unnecessary suffering near the end-of-life in low-access U.S. states. The psychological mechanisms accounting for state-level variation are poorly understood. The authors combined 5 state-level datasets that included the 50 states and national capital. PC access was measured by the Center to Advance Palliative Care 2015 state-by-state report card.¹ State-level personality differences in openness, conscientiousness, agreeableness, neuroticism, and extraversion were identified in a report on 619,387 adults. The Census and Gallup provided covariate data. Regression analyses examined whether state-level personality predicted state-level PC access, controlling for population size, age, gender, race/ethnicity, socio-economic status, and political views. Sensitivity analyses controlled for rurality, non-profit status, and hospital size. PC access is worse in states lower in openness, meaning where residents are more skeptical, traditional, and concrete. Personality theory offers recommendations for PC advocates communicating with administrators, legislators, philanthropists, and patients to expand access in low-openness states. **Abstract:** <https://goo.gl/1kwrCd>

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/>

Racial differences in health care transitions and hospice use at the end of life

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 January 2019 – Although the fragmentation of end-of-life (EoL) care [in the U.S.] has been well documented, previous research has not examined racial and ethnic differences in transitions in care and hospice use at the EoL. In this retrospective cohort study among 649,477 Medicare beneficiaries who died between July 2011 and December 2011, the mean number of care transitions within the last six months of life was 2.9 transitions for whites, 3.4 transitions for African Americans, 2.8 transitions for Hispanics, and 2.4 transitions for Asian Americans. After adjusting for age and sex, having at least four transitions was significantly more common for African Americans compared with whites, and less common among Hispanics, and Asian Americans. Having no care transition was significantly more common for Asian Americans and Hispanics, compared with African Americans and whites. Among hospice users, whites, African Americans, and Hispanics had similar length of hospice enrollment, which was significantly longer than that of Asian Americans. Non-white patients were significantly more likely than white patients to experience hospice disenrollment. Racial/ethnic differences in patterns of EoL care are marked. Future studies to understand why such patterns exist are warranted. **Abstract:** <https://goo.gl/7u3ra8>

Noted in Media Watch 10 December 2018 (#593, p.16):

- *SSM – POPULATION HEALTH* | Online – 30 November 2018 – '**Racial and ethnic differences in end-of-care in the U.S.: Evidence from the Health & Retirement Study.**' There are marked racial and ethnic disparities at the end of life (EoL), even when adjusting for a range of individual characteristics. The demand for culturally-sensitive EoL care will continue to rise due to a growing ethnically and racially diverse population of older adults. Efforts to reduce existing discrepancies should target both patients and healthcare professionals to ensure that new models of care accommodate the diverse needs of older adults. Securing these conditions for high-quality EoL care is likely to require dedicated support from governmental structures.. **Full text:** <https://goo.gl/b7WSB3>

N.B. Selected articles on racial disparities in the provision and delivery of EoL care in the U.S. noted in 16 July and 5 November 2018 issues of Media Watch (#572, p.5 and #588, p.8, respectively).

To code or not to code: Teaching multidisciplinary clinicians to conduct code status discussions

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 January 2019 – Code status discussions (CSDs) can be challenging for many clinicians. Barriers associated with them include lack of education, comfort level, and experience. This study [at an urban community teaching hospital of 500 beds serving an ethnically diverse population] found that a brief educational intervention with multipronged teaching tools improved knowledge concerning CSDs. Participants felt it provided new insights and would change their practice. This study contributes to the literature by examining CSD training across different disciplines, allowing for cross-group comparisons. Future studies should try to correlate educational interventions and clinician knowledge with clinical practice outcomes. **Abstract:** <https://goo.gl/P4a8Fy>

Non-symptomatic factors more strongly associated with high-quality end-of-life care than symptomatic factors for community-dwelling older adults with multiple chronic conditions

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 January 2019 – This study involved retrospective cross-sectional cohort analysis of secondary data derived from the National Health & Aging Trends Study (NHATS). The analytic sample included 477 NHATS participants. The rating of overall care quality was positively associated with coordination, shared decision making, respect, and spiritual and emotional support. Symptom management was unrelated to the overall quality rating, and further research is needed to illuminate the meaning of this finding. **Abstract:** <https://goo.gl/G1WwdB>

Comfort or care: Why do we have to choose? Implementing a geriatric trauma palliative care program

JOURNAL OF TRAUMA NURSING, 2019;26(1):2-9. The geriatric ... population is one of the fastest growing age groups in the U.S. As this number increases, so does the number of geriatric trauma patients. Because this group has higher mortality rates and requires more resources, a Geriatric Trauma Palliative Care Program was created at a Level 1 Trauma Center in Dallas, Texas, to provide concurrent life-saving therapies and primary palliative care (PC) to older adults. The program implemented the American College of Surgeons Trauma Quality Improvement Program Palliative Care Best Practices Guidelines¹ to better care for acute traumatic injuries as well as the specific spiritual, emotional, and psychiatric needs of the geriatric trauma PC patient and family. Using the guidelines, the team performed a gap analysis, carried out program development, created a PC pathway to guide their evidence-based practice implementation, and performed retrospective chart reviews for 3-month pre- and post-implementation analysis. The guidelines gave the team a consistent framework for implementing the basic competencies required to deliver primary PC, pain and symptom management, and end-of-life care to trauma patients. **Abstract:** <https://goo.gl/wSnd7R>

1. 'Trauma Quality Improvement Program Palliative Care Best Practices Guidelines,' American College of Surgeons, 2017. **Download/view at:** <https://goo.gl/xmyYKV>

Tackling existential distress in palliative care

NEWSGP | Online – 10 January 2019 – In the public's mind, palliative care (PC) is associated with relief of suffering. But a surprising amount of end-of-life suffering is not just physical – but existential. And for some, it can cause extreme suffering. Dr. Nicola Morgan worked as a GP for more than a decade before becoming a PC specialist on the Gold Coast, where she has helped many patients die “good deaths.” In that time, she has seen the effects of people grappling with meaning as their days come to an end. “We are complicated creatures. We are physical, emotional, and spiritual,” Dr. Morgan told *newsGP*. “I’m not talking about religion, but about what gives you meaning. If that part is suffering, that’s existential distress. In specialist PC, we see a lot of it.” But Dr. Morgan said many patients are not able to express that distress directly. “It doesn’t necessarily manifest. You have to go searching for it,” she said.



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"If someone is, within their psyche, struggling deeply, it depends on the individual as to what solution would work. If they're religious, they may need a priest. But it may be totally different." For a young woman, say, who is going to die soon and will never see her children grow up and their important journeys, you might find the most appropriate solution is to assist in her writing important letters for them to open on special occasions, so she can have closure. It's complex. "Sometimes it's about loss of roles and grieving for them, about not wanting to be in the situation you find yourself in." Dr. Morgan has found that one of the unexpected gifts of working with people who are dying is the opportunity to think these issues through.

Full text: <https://goo.gl/jXANXz>

Noted in Media Watch 12 March 2018 (#554, p.13):

- *PEDIATRIC CRITICAL CARE MEDICINE*, 2018;19(3):275-276. '**Is all suffering equal or is it time to address existential suffering.**' Although pain and symptom management is important, existential suffering is real and pervasive at the end of life and is often neglected. Existential suffering has been described in the palliative care literature as feelings of dread, powerlessness, solitude and loss of control that occurs when faced with terminal illness. It is suffering with no clear connection to physical pain and can often manifest as questioning one's spiritual connections or identity as a parent. Patients and parents of dying patients describe it as being groundless, "shaken to the core" and feelings of extreme hopelessness. **First page view:** <https://goo.gl/EgqbiR>

Noted in Media Watch 6 June 2016 (#465, p.9):

- *BRITISH COLUMBIA MEDICAL JOURNAL*, 2016;58(5):268-273. '**Addressing existential suffering.**' The author aims to demystify existentialism and provide practical tips for addressing existential suffering, even in parents and children with terminal illness. Formalized interventions that assist patients with existential issues are recommended. Physicians are encouraged to get support in exploring domains that they may feel are outside their scope of practice, such as spirituality, and encouraged to adjust boundaries in the doctor-patient relationship in palliative care settings. With the aid of a physician who addresses existential suffering, it is possible for patients to transition from feeling hopeless to feeling more alive than ever. **Full text:** <http://goo.gl/NrmH2e>

A model for occupation-based palliative care

OCCUPATIONAL THERAPY IN HEALTH CARE | Online – 7 January 2019 – This article presents a scoping review of 74 papers from the peer reviewed literature dealing with occupational therapy in palliative care (PC). Five themes emerged regarding the parameters of occupational therapy in PC: 1) The importance of valued occupations even at the end of life; 2) An exploration of how occupations change over the trajectory of a terminal illness; 3) The balance between affirming life and preparing for death; 4) Valued occupations might be doing, being, becoming, or belonging occupations; and, 5) The emphasis of a safe and supportive environment as an essential dimension for effective PC. These themes are combined to form a model to guide occupational therapy in PC. The model offers structure and direction for occupational therapists in order to offer an opportunity for clients in PC to flourish toward the end of their lives.

Abstract: <https://goo.gl/TyefXP>

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[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>

Noted in Media Watch 26 November 2018 (#591, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 November 2018 – ‘**Do healthcare professionals really understand the role of occupational therapy in hospice care?**’ This study reveals that the role occupational therapy (OT) in hospice care is misunderstood and that OT services are underutilized. Five themes are identified regarding the underutilization of OT services: 1) Lack of reimbursement; 2) Timing of referral; 3) Knowledge of the role of OT; 4) Refusal of services by family members; and, 5) Lack of OT presence in this setting. **Abstract:** <https://goo.gl/FJveYK>

Noted in Media Watch 28 May 2018 (#565, p.14):

- *PALLIATIVE MEDICINE*, 2018;32(5):960-968. ‘**Mapping the scope of occupational therapy practice in palliative care: A European Association for Palliative Care cross-sectional survey.**’ This study is the first to examine the provision of occupational therapy (OT) in palliative care in Europe. It shows there is a shared core content of OT services in direct and indirect patient care and that priority is given to clinical care activities over teaching, service development or research. OTs understand and value their role in making it possible for people facing dying to participate as fully as they wish and are able in their everyday lives but do not feel that this role is used to its full potential. **Full text:** <https://goo.gl/E6HiCd>

Assessing quality of care for the dying from the bereaved relatives’ perspective: Using pre-testing survey methods across seven countries to develop an international outcome measure

PALLIATIVE MEDICINE | Online – 10 January 2019 – Overall, the authors have developed a common, core international questionnaire (‘i-CODE’) with key questions pertaining to the quality of care for those who are dying. In addition, they have culturally adapted versions, combining the views of patient and public involvement (PPI) representatives, and, with the exception of Brazil, bereaved relatives’ views for each language. On an international basis, the i-CODE questionnaire appears to have good face and content validity. As individual questions appeared to be culturally relevant across all seven participating countries, the next part of the research process – a cross-sectional survey with bereaved relatives – is feasible and a transnational comparison of results is possible. Further assessment of the psychometric properties of the CODE™ questionnaire will be facilitated during the next steps of this research. The feedback from the PPI events and cognitive interviews was beneficial in terms of refining specific wording of questions to help with clarity and sensitivity. In particular, suggestions regarding the wording of the “demographic details” section of the CODE™ questionnaire were especially pertinent to ensure that ethnicity and religious affiliations were culturally appropriate. **Full text:** <https://goo.gl/PajPxb>

Novel application of discrete choice experiment methodology to understand how clinicians around the world triage palliative care needs: A research protocol

PALLIATIVE & SUPPORTIVE CARE | Online – 3 January 2019 – As referrals to specialist palliative care (PC) grow in volume and diversity, an evidence-based triage method is needed to enable services to manage waiting lists in a transparent, efficient and equitable manner. Discrete choice experiments (DCEs) have not to date been used among PC clinicians, but may serve as a rigorous and efficient method to explore and inform the complex decision-making involved in PC triage. This article presents the protocol for a novel application of an international DCE as part of a mixed-method research program, ultimately aiming to develop a clinical decision-making tool for PC triage. **Abstract (w. list of references):** <https://goo.gl/6AnLTu>

Noted in Media Watch 9 July 2018 (#571, p.15):

- *PALLIATIVE MEDICINE*, 2018;32(7):1246-1254. ‘**Responding to urgency of need: Initial qualitative stage in the development of a triage tool for use in palliative care services.**’ This article identifies markers of urgency, including physical and psychological suffering, caregiver distress, discrepancy between care needs and care arrangements, mismatch between current site of care and desired site of death when in terminal phase, and complex communication needs. Performance status and phase of disease are less informative when considered in isolation. Interpersonal and system-based barriers to the implementation of a palliative care triage tool are highlighted. **Abstract:** <https://goo.gl/uGHkf6>

Healthcare professionals and volunteers education in palliative care to promote the best practice: An integrative review

SCANDANAVIAN JOURNAL OF CARING SCIENCES | Online – 10 January 2019 – Family caregivers' (FCGs) empowerment can assume strategic importance in palliative care (PC). While several educational initiatives exist, a comprehensive evidence synthesis on the effectiveness of educational training on healthcare professionals and volunteers is lacking. An integrative review was conducted to explore worldwide initiatives, aiming to improve healthcare professionals and volunteers' competence in a PC setting especially in relation to the FCG. Twenty-two studies met the eligibility criteria. Multi-professional learning was reported, emphasising nurses and physician's enrolment. Only a few studies showed participants' learning outcomes. Inconsistencies in delivery mode and duration were identified. Impact evaluations were heterogeneous and relied on no validated instruments. FCGs content was addressed only in three initiatives. Further research is needed using a more reliable design, mode of delivery and impact measurement of educational training. In addition, more initiatives associated with cost-effectiveness, shorter- and longer-term clinical impact are needed. Despite the strides already made towards the establishment of an evidence base for healthcare professionals in the field of PC, greater consideration is required for family care providers in the education of healthcare professionals and respect for cultural diversity. **Abstract:** <https://goo.gl/Eg5Hwk>

Related

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(1):61-70. '**Effectiveness of the teach-back method for improving caregivers' confidence in caring for hospice patients and decreasing hospitalizations.**' This improvement project, conducted in one division of a home care agency, used a pre-test/post-test design with an interprofessional group of hospice home care clinicians to incorporate teach-back into home visits to evaluate if the use of teach-back enhanced caregiver and patient-provider communication, improved caregivers' confidence in caring for hospice home care patients, and decreased hospitalizations. **Abstract:** <https://goo.gl/UREiaP>

Web-based video-conferencing for rural palliative care consultation with elderly patients at home

SUPPORTIVE CARE IN CANCER | Online – 7 January 2019 – The purpose of this study was to gain a preliminary understanding of the experience of using mobile web-based video-conferencing (WBVC) for conducting in-home palliative care consults with elderly, rural patients with life-limiting illness. Analysis of qualitative data revealed four themes: 1) Communication; 2) Logistics; 3) Technical issues; and, 4) Trust. Participants reported they were comfortable discussing concerns by WBVC and felt it was an acceptable and convenient way to address needs. Use of WBVC improved access and saved time and travel. Fears were expressed

about lack of security of information transmitted over the Internet. **Abstract (w. list of references):** <https://goo.gl/Y2FoN9>



'End-of-life care in rural communities.'
<https://goo.gl/XAfXSz>

'National palliative medicine survey looks at urban versus rural.'
<https://goo.gl/yYCvUY>

N.B. Additional articles on PC in rural Canada noted in 5 November 2018 issue of Media Watch (#588, p.2).

Evaluating a professional patient navigation intervention in a supportive care setting

SUPPORTIVE CARE IN CANCER | Online – 5 January 2019 – Unmet supportive care needs are common among cancer patients. This study evaluates a patient navigation intervention (i.e., specially trained oncology nurse who monitors, advises, and – if needed – refers patients to supportive cancer care) in

Cont.

terms of need, satisfaction, advice uptake, and consumption of supportive cancer care. In total, 1,091 patients were offered patient navigation. Most of these patients (755) were willing to consult the patient navigator (PN). Approximately 90% of patients who completed both the intervention and the questionnaire ... perceived the PN as valuable, accessible, and reliable. Approximately 80% of respondents who needed advice regarding nutrition, fatigue, emotions, and work were adequately informed by the PN. Of the 120 respondents, 59 used some form of supportive cancer care. Most of the responding healthcare professionals ... perceived the intervention as a valuable addition to current cancer care and mentioned that the PN should be available to all patients. **Abstract (w. list of references):** <https://goo.gl/K7W3qz>

Noted in Media Watch 20 August 2018 (#577, p.15):

- *SUPPORTIVE CARE IN CANCER* | Online – 14 August 2018 – ‘**In their own words: Patient navigator roles in culturally sensitive cancer care.**’ Survey respondents described eleven interrelated navigator roles: 1) Assess and understand patient needs; 2) Tailor care to patient; 3) Build rapport/open communication; 4) Facilitate communication between patient and health care team; 5) Educate/provide resources to the patient; 6) Advocate; 7) Self-motivated learning; 8) Address barriers to care; 9) Involve/meet the needs of family or support people; 10) Educate/support health care team; and, 11) Support patient empowerment in care. **Full text:** <https://goo.gl/8GwDpg>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CANADIAN JOURNAL ON AGING* | Online – 10 January 2019 – ‘**Health care provider experiences of and perspectives on medical assistance in dying: A scoping review of qualitative studies.**’ Much of the literature on health care provider perspectives on medical assistance in dying (MAiD) is focused on the role of the physician, with some literature examining the views of nurses. Some Canadian provinces however, have implemented multidisciplinary approaches to MAiD. As a result, an improved understanding of the experiences of a variety of health care providers in the MAiD process will be important to consider as provincial MAiD plans continue to develop. This scoping review aimed to summarize the existing qualitative literature focused on provider experiences in the MAiD process. Key themes emerged across the literature that were related to the complexity of the MAiD process, the importance of relationships and communication, interprofessional roles and dynamics, and the coping process. The results of this review demonstrate the need for further investigation into the experiences of diverse MAiD providers, especially within the Canadian context. **Abstract:** <https://goo.gl/HpqrVX>

Publishing Matters

Plagiarism and predatory journals: A threat to scientific integrity

ANALES DE PEDIATRÍA, 2019;90(1):e1-e57. This article presents an analysis of the concept of plagiarism in order to show the wide spectrum of manifestations that can be considered as such when committing a transgression of intellectual property, carried out with the intention of deceiving the authors' true contribution and the originality and novelty of the information. The article describes the concurrent circumstances in intentional plagiarism, and the damage that this misconduct causes in the credibility of the scientific system, in which authorship credit is the foundation of the academic career, of the prestige of the author in the scientific community, and the basis for research funding. Some circumstances are favouring this fraud: the pressure exerted on researchers by the criteria used for promotion and reward that prioritise the quantity of works on their quality, the existence of a market for the purchase and sale of scientific articles, and the proliferation of predatory journals that operate without or minimal ethical standards. The author highlights the convenience of the adoption of criteria that prioritise the intrinsic quality of the work versus its quantity, including the active involvement of the institutions in the development of active policies for the prevention, detection, and punishment of the cases of potential fraud, and emphasize that, in the end, the prevention of fraud relies on the individual adoption of an ethical and responsible behaviour. **Full text (click on pdf icon):** <https://goo.gl/DYBKTe>



Scientific spam

UGESKR LAEGER (Danish Medical Journal), 2018;180(50). Predatory publishing has led to an increasing amount of scientific spam mails addressed to medical researchers. A total of 137 spam e-mails with scientific contents were received. The majority (88%) was automatically led to the spam filter. The mails represented various invitations from journals (77%), conferences (19%) and other (4%). Most of the mails used titles, had opening lines or flattery contents, and spelling, grammar or layout errors were common. Since spam filters are not completely accurate, screening is often necessary, however, responding to unsolicited predatory scientific spam should be avoided. **Abstract (via PubMed):** <https://goo.gl/4be3kj>

N.B. Danish language article.

[Media Watch: Access on Online](#)

International



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

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://goo.gl/frPgZ5>

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

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

[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']

Canada



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

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

ONTARIO | Acclaim Health (Palliative Care Consultation): <https://goo.gl/wGi7BD>

[Scroll down to 'Additional Resources']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <https://goo.gl/IOSNC7>

Europe



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']

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Distribution

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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.

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.

[Search Back Issues of Media Watch @ http://goo.gl/frPgZ5](http://goo.gl/frPgZ5)

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