

Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

Caregivers are in many respects often the unseen third party of prognostic communication. They are ... variably and problematically: positioned as bystander yet are key actors in the scene; expected to balance within prognosis realism and optimism; and, finally, they play a central role in the emotional work of managing the benefits and undermining effects of prediction in cancer care.

'Cancer caregivers' experiences of prognosis in Australia: A qualitative interview study' (p.6), in *BMJ Open*.

Canada

Assisted (or facilitated) death

Online government survey on medical aid in dying sees record-breaking response

CBC NEWS | Online – 23 January 2020 – The federal government has been flooded with messages from Canadians who want to weigh in on medical aid in dying. As of Wednesday evening, 229,281 Canadians had responded to the government's survey, which has been online for just a week and a half. It's an enormous figure – the largest number of responses the Department of Justice has ever seen for any public consultation. Even hot topics like cannabis and prostitu-

tion only netted about 30,000 responses each. <http://bit.ly/2Ri9ybv>

Specialist Publications

'Family physicians' perspectives on advance care planning in community-dwelling elderly patients' (p.6), in *Canadian Family Physician*.

Related:

- *THE GLOBE & MAIL* | Online – 23 January 2020 – '**New survey finds support among Canadians for broader assisted-dying law.**' As the federal government moves to revise the law on assisted dying, new survey results suggest most Canadians support medical help to end suffering even when a natural death is some time away. In a web survey conducted for The Canadian Press, polling firm Leger found 86% of respondents agreed that people with a serious, degenerative and incurable disease should be able to request and obtain medical assistance in dying (MAiD). Seventy-four per cent of those who took part said MAiD should be accessible to all people with incurable diseases, even if their death is not fast approaching. Agreement with this notion of a broader assisted-dying regime ranged from 66% in Manitoba and Saskatchewan to 84% in Quebec. There was also little variation among people who identified as supporters of the three main federal parties. <https://tgam.ca/30Nfblb>

Cont.

- QUEBEC | CBC News (Quebec City) – 21 January 2020 – ‘**Quebec to comply with ruling that struck down assisted death provisions.**’ The Quebec government will comply with a court ruling striking down parts of its medical aid in dying legislation, the province's health and justice ministers announced... The province will allow a provision stating those seeking a medically assisted death must be “at the end of life” to simply disappear from its legislation, the ministers said, without making any further amendments to the proposed law. The decision means more people will qualify for a medically assisted death, Quebec Health Minister Danielle McCann said, reminding reporters that patients will still have to meet the law’s five other criteria to qualify. Last September, Quebec Superior Court Justice Christine Baudouin invalidated the “reasonably foreseeable natural death” requirement of the Criminal Code and a section the Quebec law that states people must “be at the end of life,” which prevented access to medical assistance in dying for some. <http://bit.ly/2RIOR9h>

[U.S.A.](#)

New Jersey legislation to expand hospice and palliative care

NEW JERSEY | *Hospice News* – 22 January 2020 – New Jersey Governor Phil Murphy recently signed into law a piece of legislation designed to raise public awareness of hospice and palliative care (PC). The state’s legislature is currently mulling two additional bills intended to boost awareness and utilization of those services. The new law, designated S-3118, requires the state’s Commissioner of Health to establish a public awareness campaign to foster community-wide discussions and to promote early conversations about advance care planning (ACP) and patient preferences to improve decision-making at the end-of-life (EoL). The additional bills still under consideration include S-3116 and S-3117, which would require certain healthcare facilities to train all administrative and professional staff to complete annual training on ACP and EoL care, the use of advance directives and Physician Orders for Life-Sustaining Treatment forms, as well as provide patients with information about these services and hospice and PC. S-3116 would apply to assisted living facilities, dementia care facilities, nursing homes, comprehensive personal care homes, residential healthcare organizations, hospitals and long term care providers. Bill S-3117 would establish similar requirements for hospital emergency departments. <http://bit.ly/2NKTcWP>

Patients want to die at home, but home hospice care can be tough on families

NATIONAL PUBLIC RADIO | Online – 21 January 2020 – According to a recent Kaiser Family Foundation poll, 7 in 10 Americans say they would prefer to die at home, when the time comes.¹ And that’s the direction the healthcare system is moving, too, hoping to avoid unnecessary and expensive treatment at the end of life. Still, when it comes to where we die, the U.S. has reached a tipping point. Home is now the most common place of death, according to new research,² and a majority of Medicare patients are now turning to hospice services to help make that possible.³ Fewer Americans these days are dying in a hospital, under the close supervision of doctors and nurses. Hospice allows a patient deemed to have fewer than six months to live to change the focus of their medical care – from the goal of curing disease to a new goal of using treatments and medicines to maintain comfort and quality of life. It is a form of palliative

care, which also focuses on pain management, but can be provided while a patient continues to seek a cure or receive treatments to prolong life. Usually, hospice care is offered in the home, or sometimes in a nursing home. Since the mid-1990s, Medicare has allowed the hospice benefit to cover more types of diagnoses, and therefore more people. As acceptance grows among physicians and patients, the numbers continue to balloon – from 1.27 million patients in 2012 to 1.49 million in 2017. <https://n.pr/37h5Oga>

[Specialist Publications](#)

‘Does palliative care utilization facilitate conversion to hospice care? A qualitative study of the “soft no”’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

Cont.

1. 'Kaiser/*Economist* survey highlights Americans' views and experiences with end-of-life care, with comparisons to residents of Italy, Japan and Brazil,' *Kaiser Health News*, published online 27 April 2017. [Noted in 1 May 2017 issue of *Media Watch* (#510, p.3)] <http://bit.ly/2v1pINJ>
2. 'Changes in the Place of Death in the U.S.,' *The New England Journal of Medicine*, 2019;381(24):2369-2370. **Summary:** <http://bit.ly/35fjbfL>
3. 'Site of death, place of care, and healthcare transitions among U.S. Medicare beneficiaries, 2000-2015,' *Journal of the American Medical Association*, published online 25 June 2018. [Noted in 2 July issue of *Media Watch* (#570, p.4)] **Full text:** <http://bit.ly/2TJJIPu>

Noted in *Media Watch* 5 November 2018 (#588, p.8):

- *JOURNAL OF HOUSING FOR THE ELDERLY* | Online – 25 October 2018 – '**The motivations and consequences of dying at home: Family caregiver perspectives.**' Five family caregivers participated in semi-structured interviews about their experiences witnessing and supporting the end-of-life process of an older family member who died at home. Their stories paint a vivid picture about the motivations and consequences of the experience, including themes such as caregivers' immense feelings of uncertainty regarding their caregiving abilities and decision-making, the significance of the home environment as a symbol of comfort and security, the influence of family and social networks, and "dying well" as a social justice issue. **Abstract:** <http://bit.ly/2UrFwVh>

Noted in *Media Watch* 12 October 2015 (#431, p.9):

- *BRITISH MEDICAL JOURNAL* | Online – 7 October 2015 – '**Is home always the best and preferred place of death?**' Focusing on place of death as the key indicator of quality in end-of-life care distracts attention from the experience of dying for patients and their families. Evidence suggests that place of death is not the overriding priority. Control of symptoms, especially pain, and being accompanied by loved ones are more important. When patients wish to die at home, every effort should be made to achieve this outcome. However, until resources are in place to adequately and equitably support home deaths, the current promotion of patient choice risks raising expectations that are not realised. There are also many reasons why patients may not wish to die at home. **Abstract:** <http://bit.ly/2CVNwUw>

Diagnosed with dementia, she documented her wishes for the end. Then her retirement home said no

THE WASHINGTON POST | Online – 18 January 2020 – People with dementia are most likely to die in nursing facilities, according to new research from Duke University and Veterans Affairs Boston Healthcare System.¹ "If you've got the resources, where you've got family and paid caregivers at home, you're all set," said Karl Steinberg, a California geriatrician and hospice physician who has written extensively about dementia directives. If you're living in a facility, he said, "it's not going to happen." One key question is whether patients with dementia – or those who fear the disease – can say in advance that they want oral food and fluids stopped at a certain point, a move that would hasten death through dehydration. It is a controversial form of VSED – voluntarily stopping eating and drinking – a practice among some terminally ill patients who want to end their lives. In those cases, people who still have mental capacity can refuse food and water, resulting in death within about two weeks. Many states prohibit the withdrawal of assisted feeding, calling it basic "comfort care" that must be offered. Only one state, Nevada, explicitly recognizes an advance directive that calls for stopping eating and drinking. And that's via a little-known law that took effect in October. Critics of such documents, however, say they could lead to forced starvation of incapacitated people. <https://wapo.st/2NHVBBv>

1. 'Changes in the place of death in the U.S.,' *The New England Journal of Medicine*, 2019;381(24):2369-2370. [Noted in 16 December 2019 issue of *Media Watch* (#644, p.2)] **Access article at:** <http://bit.ly/35fjbfL>

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Noted in Media Watch 25 November 2019 (#641, p.7):

- *AUSTRALASIAN JOURNAL ON AGEING* | Online – 19 November 2019 – ‘**Voluntary stopping of eating and drinking in advance directives for adults with late-stage dementia.**’ There is legal uncertainty in Australia around whether an advance directive (AD) to voluntarily stop eating and drinking will be followed should the adult become incompetent. Voluntary stopping of eating and drinking should be viewed in law as a form of “treatment” that competent adults can nominate in ADs, thereby providing dementia patients with the opportunity to choose in advance, if they wish, to end their life legally, with dignity and comfort, and in a manner that does not implicate others in criminal behaviour such as assisted suicide, acceleration of death or euthanasia. **Abstract:** <http://bit.ly/2pFxn28>

Noted in Media Watch 27 August 2018 (#578, p.9):

- *THE HASTINGS REPORT*, 2018;48(4):2. ‘**Advance directives and dementia.**’ A competent person can avoid the onset of dementia by refusing life-sustaining medical care and by voluntarily stopping eating and drinking (VSED)... A competent person can also try to limit the duration of dementia by drafting an advance directive (AD) that sets bounds on the life-sustaining care, including artificial nutrition and hydration, that medical caregivers can provide when the person no longer has the capacity to make her own medical decisions. But between these two strategies there can lie a significant gap. A person could live with moderate to severe dementia for a considerable time, no longer able to VSED yet also not yet requiring the life-sustaining care forbidden by an AD. **Abstract:** <https://goo.gl/DZ5kAJ>

International

Assisted (or facilitated) death

Law restricting doctors from initiating euthanasia talk is “gag clause,” academics say

AUSTRALIA (Victoria) | *The Brisbane Times* – 20 January 2020 – A law that bans Victorian doctors from instigating conversations about voluntary assisted dying with terminally ill people poses an “unprecedented, unwarranted infringement on communication between health practitioners and their patients,” a group of medical ethicists warn. In an article published in the *Medical Journal of Australia*..., the academics conclude a section of the state’s act which prohibits doctors from initiating discussions about physician-assisted death operates as a “gag clause,” and undermines their ethical obligations to patients.¹ [The authors] also argued concerns that doctors may coerce terminally ill people into taking their own lives lacked any robust evidence. “The stated intent ... is not to discourage open discussion, but to ensure that patients are not coerced or unduly influenced into accessing voluntary assisted dying,” the authors wrote. “Although this aim is undeniably important, the Ministerial Advisory Panel on Voluntary Assisted Dying offered no evidence from other jurisdictions that such coercion has previously occurred. Indeed, it cited research indicating that “fears that people from particular groups will be pushed

into making such requests are ill-founded.”
<http://bit.ly/2R652gf>

Specialist Publications

‘**End-of-life care for people with advanced dementia and pain: A qualitative study in Swedish nursing homes**’ (p.6), in *BMC Nursing*.

‘**Building specialized palliative care for the Czech Republic: A fifteen-year leadership journey in a developing country**’ (p.9), in *Journal of Palliative Medicine*.

‘**End-of-life decision-making in Asia: A need for in-depth cultural consideration**’ (p.11), in *Palliative Medicine*.

‘**Mapping palliative and end-of-life care research in Australia (2000-2018)**’ (p.11), in *Palliative & Supportive Care*.

‘**Digital story-telling research methods: Supporting the reclamation and retention of indigenous end-of-life care customs in Aotearoa New Zealand**’ (p.11), in *Progress in Palliative Care*.

1. ‘Victoria’s Voluntary Assisted Dying Act: Navigating the Section 8 gag clause,’ *Medical Journal of Australia*, published online 20 January 2020. **Access article at:** <http://bit.ly/30AhKqA>

Specialist Publications

Does palliative care utilization facilitate conversion to hospice care? A qualitative study of the “soft no”

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 23 January 2020 – Facilitating patient conversion to hospice at end of life is a prominent clinical concern. Enrollment in outpatient palliative care (PC) services is often assumed to encourage seamless transition to hospice care, but this has not been demonstrated. Moreover, decisions to convert from PC to hospice are generally treated as dichotomous, thus hampering our ability to understand decision processes. Patients [i.e., study participants] rarely refused hospice outright but more often postponed using a “soft no,” in which they neither accepted nor overtly refused hospice. Justifications patients and caregivers offered for why hospice was not needed (yet) appeared in these themes: 1) Not seeing the value added of hospice; 2) Assuming the timing is premature; and, 3) Relying on extensive health-

related support networks that justify or endorse continuation of active care. Despite assumptions to the contrary, benefits associated with utilization of outpatient PC services have the potential to incentivize the delay of hospice in some cases. Clinical interactions with outpatient PC patients should consider the influence of these broad social support systems when discussing hospice options. **Abstract (w. list of references):** <http://bit.ly/38x4dTr>

Publishing Matters

‘Do journals contribute to the international publication of research in their field? A bibliometric analysis of palliative care journal data’ (p.12), in *Palliative Medicine*.

The quality of end-of-life care among intensive care unit versus ward decedents

AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE | Online – 15 January 2020 – Admissions to intensive care units (ICUs) are common during terminal hospitalizations, but little is known about how ICU care affects the end-of-life (EoL) experience for patients dying in hospitals and their families. The authors measured the association between ICU care during terminal hospitalization and family ratings of EoL care for patients who died in 106 Veterans Affairs hospitals from 2010 to 2016. Of 57,550 decedents, 48.8% had a survey completed by a family member or close contact. In adjusted models, ICU-only care was associated with more frequent optimal ratings than no ICU care, including overall excellent care, care consistent with preferences, and having pain controlled. Among patients with mixed care, increasing ICU time was associated with higher ratings on these same measures. Among hospital decedents, ICU care was associated with higher family ratings of quality of EoL care than ward care. Reducing ICU use among hospital decedents may not improve ICU quality, and efforts to understand how ICU care improves EoL quality could help provide better care outside ICUs. **Abstract:** <http://bit.ly/2RLK0md>

N.B. Additional articles on palliative and EoL care in ICU noted in 13 January 2020 issue of Media Watch (#648, pp.1-2).

Dying-well: The contribution of leisure services to hospice care

ANNALS OF LEISURE RESEARCH | Online – 20 January 2020 – Leisure has suffered a neglect in the palliative care literature, with clinically driven narratives often overlooking the pivotal role leisure plays within this landscape. A problem inherent in much of the existing literature is that although scholars agree about the blending of hedonia and eudaimonia, the lines between them are blurred. The authors contribute to the existing literature by fleshing out the middle ground of the hedonia and eudaimonia continuum. Here, the authors’ term this point of equilibrium transitional leisure, which projects a liminal state of well-being. Interview data was collected from in/day/outpatients, families, and the bereaved associated with multiple hospices. Findings detail the contribution of therapeutic services, therapeutic spaces, and therapeutic places to well-being. Conclusions add a further dimension to the well-being literature, an appreciation of “dying-well” and the middle ground of transitional leisure. Practical implications for enhancing service delivery are presented. **Abstract:** <http://bit.ly/2NRTE5o>

End-of-life care for people with advanced dementia and pain: A qualitative study in Swedish nursing homes

BMC NURSING | In Press – 21 January 2020 – This study shows that nurses face several demanding challenges when caring for people with advanced dementia (PWAD) and pain at the end of life. One of the main issues was the difficulty in communicating with these persons, resulting in uncertain pain assessment. This results in difficulties in separating pain from anxiety and in balancing the benefits and risks of morphine administration. Relatives can significantly influence the assessment and management of pain, both as interpreters of pain behaviour and by questioning the care given. Factors facilitating good palliative care and pain management included having good relationships with the other healthcare personnel, having extensive relevant professional experience, and having enough time to care for the PWAD and their relatives. The many challenges can affect the care of this growing and vulnerable group negatively and, therefore, it is crucial to promote more research in this area. The authors found that specifically trained specialist nurses are sorely needed at nursing homes in order to meet these challenges with the appropriate skills and knowledge. Additionally, there should be resources and strategies available for informing and involving family members in the care as they are often unfamiliar with the considerations involved in decisions (such as whether to administer morphine or not). **Full text:** <http://bit.ly/2RByrxS>

Noted in Media Watch 9 December 2019 (#643, p.8):

- *BMC NURSING* | Online – 29 November 2019 – ‘**Critical nursing and healthcare aide behaviors in care of the nursing home resident dying with dementia.**’ The critical behaviors described by nurses and healthcare aides in this Canadian study [conducted between January 2014 and March 2015] provides emerging evidence of best practices in care of those with dementia and their families, particularly near the end of life. All of these behaviors served to achieve the overarching goal of resident comfort – a salient outcome articulated in the European Association for Palliative Care white paper defining optimal palliative care (PC) in older people with dementia¹ and the World Health Organization’s global perspective on PC. **Full text:** <http://bit.ly/2LkgZeO>

1. ‘White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,’ *Palliative Medicine*, published online 4 July 2013. [Noted in 8 July 2013 issue of Media Watch (#313, p.10)] **Full text:** <http://bit.ly/2P53RLM>

Cancer caregivers’ experiences of prognosis in Australia: A qualitative interview study

BMJ OPEN | Online – 19 January 2020 – Prognosis communication is an interpersonal, collective process, with consequences felt much more broadly than within the experiences of patients alone (or clinicians who have to manage the delivery of such information). Caregivers are in many respects often the unseen third party of prognostic communication. They are, as they self-describe in this study, variably and problematically: positioned as bystander yet are key actors in the scene; expected to balance within prognosis realism and optimism; and, finally, they play a central role in the emotional work of managing the benefits and undermining effects of prediction in cancer care. Yet, most work on the dynamics of delivering and receiving prognoses has tended to conceal caregivers within the broader lay reception of forecasting in oncology. The authors offer new insight into the often sidelined, yet still vital experiences of caregivers, revealing their experiences of cancer forecasting in contexts where there is considerable uncertainty about the patient’s future. **Full text:** <http://bit.ly/2NIPD3b>

Family physicians’ perspectives on advance care planning in community-dwelling elderly patients

CANADIAN FAMILY PHYSICIAN, 2020;66(1):e21-e29. This study explored a range of perspectives on advance care planning (ACP) among a sample of Canadian family physicians (FPs), most of whom are involved in undergraduate medical education and had received no formal ACP training. The authors found that FPs felt responsible for playing a leading role in ACP, but this might be influenced by the involvement of other healthcare providers. Participants also had different thresholds for initiating these conversations, with some physicians addressing ACP before and others during a health crisis. This variation

Cont.

can be attributed to differing ideas about the role and effects of palliative care (PC), previous patient encounters, and physician-specific factors. For the latter, physicians who solely practised in the clinic setting revealed that they frequently were not aware of the effects of ACP, owing to decreased interaction with patients near the end of life. This is a key aspect to address if FPs are to play an important role in ACP. Multiple participants also mentioned that they will always address ACP if the patient brings up the topic, highlighting how delivering early PC requires a cultural shift, not only for providers, but for the general public as well. **Full text:** <http://bit.ly/3aGSaET>

Team well-being and resilience practices in hospice and palliative care

INTERNATIONAL JOURNAL OF WHOLE PERSON CARE, 2020;7(1):33. High functioning, resilient teams do not happen by chance. Teams, similar to individuals, need to be educated, nurtured and formed over time, by a consistent vision and process. With proper team formation, the compassionate care of patients, families and colleagues can be developed, modeled and reinforced. Self-compassion is another focus to help caregivers cope with the stresses of the work and mitigate against burnout. The primary intervention discussed is a regularly scheduled reflection process, e.g., 30 minutes weekly or 90 minutes monthly, with a pediatric hospice team, an inpatient palliative care (PC) team and an outpatient PC team. The reflection process incorporates mindful meditation, journaling, listening exercises, individual and group reflection to encourage and practice self-awareness, self-reflection, greater emotional intelligence and leadership skills. Qualitative feedback from team members, patient, family and colleague satisfaction scores has been positive. Buy-in from all team members, initially, was difficult, but over time, all team members have recognized the value of the process and have incorporated the exercises not only in their work, but in their personal lives and other roles/jobs. Other key success factors are organizational support for time for this process and individual champions to develop and lead the reflective process. The workshop will include a demonstration of exercises used in team reflections with learner participation. **Abstract:** <http://bit.ly/37qOLL1>

Related:

- *JOURNAL OF MEDICAL ETHICS* | Online – 24 January 2020 – ‘**Communities of practice: Acknowledging vulnerability to improve resilience in healthcare teams.**’ The majority of healthcare professionals regularly witness fragility, suffering, pain and death in their professional lives. Such experiences may increase the risk of burnout and compassion fatigue, especially if they are without self-awareness and a healthy work environment. Acquiring a deeper understanding of vulnerability inherent to their professional work will be of crucial importance to face these risks. From a relational ethics perspective, the role of the team is critical in the development of professional values which can help to cope with the inherent vulnerability of healthcare professionals. **Abstract:** <http://bit.ly/2RM6kfq>

Noted in Media Watch 16 December 2019 (#644, p.12):

- *SUPPORTIVE CARE IN CANCER* | Online – 6 December 2019 – ‘**Resilience in palliative healthcare professionals: A systematic review.**’ Exposure to end-of-life and chronic illness on a daily basis may put palliative healthcare professionals’ well-being at risk. Resilience may represent a protective factor against stressful and demanding challenges. From the systematic synthesis, palliative care providers’ resilience revealed to be related to other psychological constructs, including secondary traumatic stress, vicarious posttraumatic growth, death anxiety, burnout, compassion satisfaction, hope and perspective taking. A model on palliative healthcare providers’ experience and the role of resilience is proposed. **Abstract (w. list of references):** <http://bit.ly/36j8Gbr>

N.B. Additional articles on burnout, compassion fatigue and resilience noted in this issue of Media Watch.

Health professionals' experiences of grief associated with the death of pediatric patients: A systematic review

JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS | Online – 8 January 2020 – There has been some research into health professionals' grief experiences, but there has not been a review that synthesizes the findings of these experiences. Other related reviews have focused on prenatal, perinatal or adult deaths or the coping strategies employed by health professionals. The synthesized findings from this review highlight the varied reported experience of grief in health professionals. The methodological quality and reporting of studies, however, led to decreased confidence in the synthesized findings and recommendations arising from this review. Healthcare professionals should be aware of the potential for experiencing grief when a patient dies and the compounding and alleviating factors associated with this. Further research could expand participant and language limitations, and improve methodological quality and reporting. **Abstract:** <http://bit.ly/38FCy2X>

An interdisciplinary framework for palliative and hospice education and practice

JOURNAL OF HOLISTIC NURSING | Online – 20 January 2020 – Leading highly functional healthcare teams in all practice settings is sustained through the identification of a conceptual framework to guide education and practice. This article presents an interdisciplinary framework for palliative and hospice education and practice. The framework builds on theoretical caring to convey elements of relational, holistic and compassion; articulates interprofessional tenets for guiding values; and, aligns with constructs for palliative and hospice best practices. The framework invites those at the bedside and in leadership to be intentional in attending to education and the necessary activities that address the day-to-day operations of palliative and hospice care, as well as, honoring all interdisciplinary collaboration that supports quality outcomes and inspires actions that transform. **Abstract (w. list of references):** <http://bit.ly/30lbn4G>

Related:

- *CLINICAL JOURNAL OF ONCOLOGY NURSING*, 2020;24(1):E1-E6. 'Palliative care communication: Outcomes from COMFORT, a train-the-trainer course for providers.' 355 oncology nurses attended the two-day course on communication for oncology nurses. This study used 6- and 12-month follow-up data from nurses who provided feedback on the progress of these goals. Nurses taught an additional 9,720 oncology providers, conducted needs assessments of communication processes, and initiated institution-wide palliative care communication training. Barriers to completing outcome goals included a lack of institutional support, specifically an absence of leadership, financial backing, and dedicated time. **Abstract:** <http://bit.ly/3auwDzk>

Organ donation at the end of life: Experiences from the 3 Wishes Project

JOURNAL OF INTENSIVE CARE MEDICINE | Online – 21 January 2020 – The 3 Wishes Project (3WP) promotes holistic end-of-life care in the intensive care unit to honor dying patients, support families, and encourage clinician compassion. Organ donation is a wish that is sometimes made by, or on behalf of, critically ill patients. The authors describe the interface between the 3WP and organ donation as experienced by families, clinicians, and organ donation coordinators. The central theme describes the mutual goals of the 3WP and organ donation – emphasizing personhood and agency across the temporal continuum of care. During family decision-making, conversations encouraged by the 3WP can facilitate preliminary discussions about donation. During preparation for donation, memory-making activities supported by the 3WP redirect focus toward personhood. During postmortem family care, the 3WP supports families, including when donation is unsuccessful, and highlights aspirational pursuits of donation while encouraging reflections on other fulfilled wishes. Organ donation and the 3WP provide complementary opportunities to engage in value-based conversations during the dying process. The shared values of these programs may help to incorporate organ donation and death into a person's life narrative and incorporate new life into a person's death narrative. **Abstract (w. list of references):** <http://bit.ly/38FpnPB>

N.B. Additional articles on organ transplantation in the context of palliative care noted in 28 October 2019 issue of Media Watch (#637, p.12).

Experiences with counselling to people who wish to be able to self-determine the timing and manner of one's own end of life: A qualitative in-depth interview study

JOURNAL OF MEDICAL ETHICS | Online – 23 January 2020 – In The Netherlands, Foundation De Einder offers counselling to people who wish to be able to self-determine the timing and manner of their end of life (EoL). This study confirms the idea that having the means available to be able to end your own life in a respectable manner can provide people with reassurance and can increase their quality of life. It can, however, also give rise to new concerns like worrying about the shelf-life of medication or not losing the medication. This study also makes clear that counselling entails more than just providing information on (collecting) medication. Counsellors can play an important role for people who wish to self-determine the timing and manner of their EoL, by having an open non-judgemental attitude, providing trustworthy information and being available. These positively valued aspects of demedicalised assistance in suicide can provide recommendations for physicians taking care of patients who wish to self-determine the timing and manner of their EoL. **Full text:** <http://bit.ly/2NVfjKm>

Building specialized palliative care for the Czech Republic: A fifteen-year leadership journey in a developing country

JOURNAL OF PALLIATIVE MEDICINE | Online – 23 January 2020 – Since its creation, the Czech Republic has developed an advanced health system and social system. Life expectancy at birth has increased by an average of 7 years in only 20 years. However, polymorbidity and multicausality have now become topics of concern. Yet, the health system and social system were not designed for these patients nor are healthcare professionals trained and willing to assess and address clinical needs of fragile, chronically ill, and incurable patients. This is true in much of the developing world where initial improvements have led to this new population-based challenge. In that sense, the Czech Republic is an example of what needs to happen in developing countries. Inpatient hospice care, which has been developing in the Czech Republic since 1993, is not the answer to this problem. Rather, approaches to ensure that the early introduction of palliative care (PC) in the course of serious illness care, personalized medicine, and a multidisciplinary approach in the system is required. Focusing only on terminal illness care is insufficient. Beginning in 2005-2006, the country has worked to create a system of education and clinical services in specialized PC in the health and social system. This article seeks to describe the leadership steps of this systemic change in the Czech Republic with the objective of helping others make the same journey. **Abstract:** <http://bit.ly/3aHVDDm>

The top ten things that must be known about end-of-life therapy in patients with advanced cancer

MAGAZINE OF EUROPEAN MEDICAL ONCOLOGY | Online – 16 January 2020 – End of life (EoL) is an issue that affects every human being sooner or later. Several aspects at the EoL should not be neglected to achieve good symptom control. Basic knowledge and skills on symptom control and palliative care (PC) are important to support patients in this threatening phase of their life. PC should not be provided only at the EoL. The concept of early integration of PC is increasingly coming into focus. Nevertheless, at the EoL there are some important facts and issues that should be taken into account. This short article provides a list of ten important facts at the EoL that are important for the authors. **Abstract (w. list of references):** <http://bit.ly/2vmTIJP>

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>



Why do palliative care services grow so slowly?

PALIAȚIA, 2020;13(1). In this issue of *Paliatja*, two articles indicate that the availability of palliative care (PC) services is still “problematic.”^{1,2} In Romania, PC services started 28 years ago, but today only 12% of the need is covered. In Albania, PC services are developing slowly, despite the effort and enthusiasm of Albanian healthcare workers. Why is the development and availability of PC, despite scientific evidence, problematic? World Health Organization lists various barriers: 1) Lack of awareness among policy-makers, health professionals and the public about what PC is, and the benefits it can offer patients and health systems; 2) Cultural and social barriers, such as beliefs about death and dying; 3) Misconceptions about PC, such as that it is only for patients with cancer, or for the last weeks of life; and, 4) Misconceptions that improving access to opioid analgesia will lead to increased substance abuse. These barriers sound very reasonable and in line with the experiences of many pioneers in PC. Some experts see a solution to overcome these barriers in improving the quality of PC, especially the education and training in PC. **Full text:** <http://bit.ly/37mBd0A>



1. ‘Palliative care in Romania for 2019,’ *Paliatja*, 2020;13(1). **Abstract:** <http://bit.ly/3awPkSY>
2. ‘Integration of palliative care in undergraduate and postgraduate training programs in Albania,’ *Paliatja*, 2020;13(1). **Abstract:** <http://bit.ly/2TNg2kd>

N.B. Additional articles on PC in Romania and Albania noted in 28 January 2019 and 13 June 2016 issues of *Media Watch* (#599, p.13, and #466, p.11, respectively).

Perspectives of elders and their adult children of Black and minority ethnic heritage on end-of-life conversations: A meta-ethnography

PALLIATIVE MEDICINE | Online – 21 January 2020 – This meta-ethnography indicates the potentially inhibitory influence of adult children in the preparatory end-of-life (EoL) decision-making of their parents, particularly in Black and minority ethnic communities. It demonstrates the complexities of this influence when those children become the primary decision-makers for their parents who are dying. It has explored a number of the reasons why there has been little discussion of the older person’s preferences, and the whole situation invokes a high level of anxiety for those adult children. Culturally curated education has been found to be helpful. Further exploration of what this might look like is needed, and how this may be also targeted at a range of family members. Understanding the

perspectives and experiences of adult children of people from Black and minority ethnic heritage about having EoL conversations may be a useful next step in developing this work. **Full text:** <http://bit.ly/2Rg4m88>

Extract from *Palliative Medicine* article

Focus is needed on the role played by adult children about their perspectives on having end-of-life (EoL) conversations with their parents. This could lead the way for innovative community engagement in the development of public health palliative care (PC) that may result in more effective EoL care planning and engagement with PC provision.



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

End-of-life decision-making in Asia: A need for in-depth cultural consideration

PALLIATIVE MEDICINE | Online – 20 January 2020 – Facilitating end-of-life decision-making is essential, yet challenging task for healthcare professionals. It is especially so in Asia where family-centered decision-making and non/partial-disclosure remain the cultural norm. Asia hosts many countries and regions, which are hosts to a variety of different cultures and traditions. Asian patients tend to value harmony in family relations over the absolute autonomy, and defer decision-making to families and healthcare professionals. In general, Asian patients, particularly the elderly, have low level of autonomy. They are even reluctant to appoint durable powers of attorney to indicate their favored family member. Moreover, patient involvement in decision-making may not be associated with higher quality of life in Asia. **Full text:** <http://bit.ly/2ujkson>

Mapping palliative and end-of-life care research in Australia (2000-2018)

PALLIATIVE & SUPPORTIVE CARE | Online – 20 January 2020 – This review presents a comprehensive search of the literature across almost two decades in Australia in the palliative care (PC) setting. It covers a breadth of research topics and highlighted urgent areas for further research. The authors' review identified 1,405 Australian PC research publications between January 2000 and December 2018. Nearly 40% of the studies were quantitative (39%) and a third were qualitative studies (31%). The remainder of the studies were reviews, mixed methods, quality improvement projects, and others. One-third (30%) of the research was done with carers' participants followed by nurses (22%) and doctors and physicians (18%). The most frequently reported diagnosis in the studies was cancer with 42% of the publication total. The most frequently explored theme was physical symptoms (such as pain, breathlessness, nausea, delirium, and dyspnea) with a total of 16% of all articles followed by communication (15%). There was a large gap to the next most frequently explored theme with service delivery (9%) and coordination of care (8%). Assessment of patients (7%), end-of-life decision-making (6%), and rural/regional (6%) all produced a similar number of publications. Very few studies addressed topics such as quality of life, E-Health, after-hours care, spirituality, and health economics. Moreover, there were only 15 (1%) studies focused on the last days of life. **Abstract (w. list of references):** <http://bit.ly/2RBjdsC>

Digital story-telling research methods: Supporting the reclamation and retention of indigenous end-of-life care customs in Aotearoa New Zealand

PROGRESS IN PALLIATIVE CARE | Online – 17 January 2020 – Information about traditional end-of-life care customs was gathered from Māori New Zealanders. How health and palliative care (PC) services helped or hindered families to use their customs within different healthcare settings was also examined. Kaupapa Māori Research and social constructivist methods were employed to conduct face-to-face interviews with 61 Māori families..., plant medicine healers, spiritual practitioners and health and PC providers. Of these, sixteen family representatives participated in a digital story telling workshop. A Kaupapa Māori thematic analysis confirmed earlier findings that the digital storytelling method was a useful technique to record Māori traditional caregiving customs. Subject material aligned with four dominant themes; 1) "Whānau manaaki," where the mana (value, prestige, authority) of family was given visibility and was celebrated; 2) The "importance of wairuatanga" provided insight into the place of Māori spirituality; 3) The "importance of rongoā rākau" highlighted the role of traditional plant medicines; and, 4) The "cultural support provided by health professionals" reflected the care values health and PC professionals should ideally adopt. **Abstract:** <http://bit.ly/2Rxkm4E>

N.B. Additional articles on Māori beliefs and practices in the context of end of life and end-of-life care noted in 27 August 2018 issue of Media Watch (#578, p.15).

Publishing Matters

Do journals contribute to the international publication of research in their field? A bibliometric analysis of palliative care journal data

PALLIATIVE MEDICINE | Online – 23 January 2020 – Research is important internationally, impacting on health service provision and patient benefit. Journals play an important dissemination role, but there may be geographical bias, potentially affecting access to evidence. To understand if there is a relationship between the continent of journals and that of contributing authors, the authors of this study analyzed five journals: three published in Europe (*Palliative Medicine*, *BMJ Supportive & Palliative Care*, and *BMC Palliative Care*) and two in North America (*Journal of Pain & Symptom Management* and *Journal of Palliative Medicine*). Authors were from 30+ countries, but mostly North America (54.18%) or Europe (27.94%). The odds of an author being from a North American institution increase 16.4 times ... if the region of journal publication is North America. The odds of an author being from a European institution is 14.0 times ... higher if the region of journal publication is Europe. Publishers, editors and authors are concentrated in North America or Europe. North American authors are more present in North American journals and European authors in European journals. This polarised approach, if replicated across readerships, may lead to research waste, duplication, and be sub-optimal for healthcare development. **Abstract (w. list of references):** <http://bit.ly/3aCr8i5>

Media Watch: Editorial Practice

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

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International



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Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://BIT.LY/2SWDYWP>

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Australia

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

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Canada



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

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

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2XC24jA>

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Barry R. Ashpole, Ontario CANADA

e-mail: barryashpole@bell.net