

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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The Last Aid Course has a huge potential to enhance public discussion about death and dying. One might assume that the course would help to empower people to engage in palliative care provision at home, and thus increase the number of home deaths.

'Citizens appreciate talking about death and learning end-of-life care: A mixed-methods study on views and experiences of 5,469 Last Aid Course participants' (p.11), in *Progress in Palliative Care*.

Canada

The grim future of palliative care in British Columbia

BRITISH COLUMBIA | *Surrey Now-Leader* – 26 February 2021 – The Fraser Health Palliative Care Program (FHPCP) was once recognized by Dr. José Pereira, co-founder of Pallium Canada, as one of the three best palliative programs in Canada. This is no longer the case. Today, Delta Hospice had its own building taken away by the Fraser Health authority for refusing to offer medical assistance in dying (MAiD) on its premises, despite it being available in the neighboring building. Dr. Neil Hilliard, former Program Medical Director of the FHPCP, recently testified at [Canada's] Senate as part of a study on Bill C-7, a bill to expand access to euthanasia for those not near death, and his submission was an eye opener. Dr. Hilliard walked the Senate through the sad story of how after the implementation of MAiD at the federal level in 2016, and the election of a New Democratic Party government in British Columbia in 2017, we saw the speedy dismantling of our top-notch palliative care (PC) program, which led to resignations and loss of service. Although "Fraser Health-led patient and family focused research in the palliative approach to care was recognized internationally as a leader in its research

in treatment of intractable symptoms at the end of life, such as treating unbearable pain or distressing confusion," things began to fall apart quickly. Dr. Hilliard testified that "The Fraser Health solution to providing enough resources for MAiD has included using scarce PC resources for the provision of MAiD." <http://bit.ly/37Sng8m>

Specialist Publications

'COVID-19, promotion and provision of palliative care: Reaching out, accounting for linguistic diversity' (p.7), in *Global Health Promotion*.

'Including the spiritual dimension in multimodal pain therapy. Development and validation of the Spiritual Distress & Resources Questionnaire (SDRQ)' (p.5), in *Journal of Pain & Symptom Management*.

'A qualitative exploration of patient and family caregiver needs when transitioning from hospital to home in palliative care' (p.10), in *Journal of Pain & Symptom Management*.

Cont.

Related:

- BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 21 February 2021 – ‘**Delta Hospice Society tells its side to Canadian Senate.**’ The introduction of medical assistance in dying (MAiD) has had the unintended consequence of creating a political movement which threatens to decimate the 50-year-old medical discipline of palliative care (PC). “Our not-for-profit society has a constitution, purpose, and a membership that does not include MAiD as part of our ethos. We follow the philosophy of every international PC organization in the world ... that MAiD is not part of PC. We declined to provide MAiD because it is not part of the provision of hospice or PC. In February 2020, Fraser Health provided 365 days’ notice to end its service agreement with the society without cause. <http://bit.ly/3dCsaI2>

N.B. Search back issues of Media Watch for additional reports on DHS at: <http://bit.ly/2ThijkC>

Noted in Media Watch 23 December 2019 (#645, p.1):

- BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 18 December 2019 – ‘**Canadian palliative society supporting Delta Hospice.**’ The public and many healthcare providers have had a longstanding fear that hospice and palliative care (PC) hastens peoples’ deaths, something that will be made worse if facilities are forced to provide medical assistance in dying (MAiD). That’s what the Canadian Society of Palliative Care Physicians (CSPCP) is saying in a letter to the province’s Health Minister Adrian Dix in support of the Delta Hospice Society... A CSPCP submission to a federal special joint committee on MAiD as well as a joint statement with the Canadian Hospice Palliative Care Association note hospice and PC and MAiD substantially differ in philosophy, intent and approach.^{1,2} <http://bit.ly/2r8VuH3>
 - ‘Presentation to Special Joint Committee on Physician-Assisted Death,’ Canadian Society of Palliative Care Physicians, July 2016. **Download/view at:** <http://bit.ly/38TNbjj>
 - ‘Joint Statement Regarding Palliative Care and Medical Assistance in Dying,’ Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, December 2019. [Noted in Media Watch 2 December 2019 (#642, p.1)]. **Download/view at:** <http://bit.ly/33mmlad>

International

Making Every Young Adult Count: Estimating Current and Future Prevalence of Young People with Life-limiting and Life-threatening conditions in England

U.K. (England) | Together for Short Lives (Bristol) – 25 February 2021 – New research ... shows that the number of young adults with life-limiting conditions has risen significantly over the last eight years. *The Making Every Young Adult Count...* study, conducted by the University of York and University of Leeds, reveals that the total number of young adults (aged 14-25 years) with life-limiting conditions in England has increased from 27,316 in 2009-2010 to 38,261 in 2017-2018 – an increase of 40%. This figure includes those diagnosed in both childhood and young adulthood. Looking just at the number of young people with a life-limiting condition who were diagnosed in childhood, the increase is higher, rising from 16,107 in 2009-2010 to 24,773 in 2017-2018, an increase of 53%. This research provides valuable insight into the numbers of children who are likely to make the transition to adult services. The data will help services to better plan their support for young people and families in preparing to move on to adult services and will also help commissioners to fund the right services.

The *Make Every Young Adult Count...* findings are based on routinely collected hospital and death certificate data from England to provide an update of current numbers and prevalence of young people with a life-limiting condition and estimate future prevalence. <https://bit.ly/3dNHDMa>

Specialist Publications

‘Evaluating the integration of palliative care in national health systems: An indicator rating process with European Association for Palliative Care task force members to measure advanced palliative care development’ (p.5), in *BMC Palliative Care*.

‘A survey of bereavement care provision in the U.K. and Ireland during the COVID-19 pandemic’ (p.5), in *BMJ Open*.

‘Preparing nurses for palliative and end of life care: A survey of New Zealand nursing schools’ (p.11), in *Nursing Education Today*.

A Snapshot of Palliative Care Services in Australia

AUSTRALIA | PM Glynn Institute (Australian Catholic University) – 24 February 2021 – The current debate on voluntary assisted dying (VAD) naturally prompts a discussion of the current state of palliative care (PC) in Australia. PC, namely its provision, should be an important consideration in the debate on VAD. Ensuring access and equity, both underlying principles of social justice, is essential. This means that PC should not only be available to everyone who needs it, but also available to members of society who are more disadvantaged than others. In light of this, and with VAD having been legalised in Victoria in 2018, in Western Australia in 2019, and being under consideration in other states, it is important that before other parliaments follow suit, they first ensure that quality PC is accessible and equitable, and that gaps in provision are addressed. For these reasons, PC needs to be a primary factor in the current debate on VAD. The aim of this report is to provide an overview of PC services in Australia, by looking at it through the lens of the two

mentioned principles – access and equity. As such, this report: 1) Investigates and explores patterns in PC service provision, and in some cases, analyses and compares changes over time; 2) Identifies gaps in PC provision; and, 3) Given the gaps, identifies areas for policy action. **Download/view report at:** <http://bit.ly/37KQMkV>

Extract from PM Glynn Institute report

One of the challenges encountered while undertaking this report was the lack of comprehensive data on PC. Data collection on PC provision is captured by episodes of hospitalisation rather than unique cases of PC utilisation. If supply and demand estimation or any econometric modelling is to be undertaken, it will be hampered by the lack of data on unique cases. Capturing unique cases would be invaluable to improvement and innovation in service planning – factors that are essential in addressing issues related to quality, accessibility and equity in PC provision.

N.B. The Catholic Church operates 80 hospitals in Australia. It also operates more than 550 residential aged care facilities (or more than 25,000 residential aged care beds) and 7,000 senior dwelling units. The Catholic Church also supports 36,500 home care and support consumers.

Noted in Media Watch 8 February 2021 (#703, p.2):

- AUSTRALIA | Palliative Care Australia – 3 February 2021 – **‘Government urged to increase investment in palliative care.’** Palliative Care Australia (PCA) has called on the Commonwealth Government to invest a further \$365 million to meet the growing palliative care (PC) needs of people in the community, in hospitals and in residential aged care. Three key funding initiatives are contained in PCA’s ‘Pre-Budget Submission’ and form a comprehensive suite of funding measures designed to address a system that is failing to meet the demand for PC in Australia.¹ PCA’s recommendations are informed by a KPMG report ‘Investing to Save: The Economics of Increased Investment in Palliative Care in Australia,’² commissioned by PCA in 2020. <http://bit.ly/2MRgOvn>

1. ‘Pre-Budget Submission: Palliative Care – its more than you think,’ Palliative Care Australia, February 2021. **Download/view submission at:** <http://bit.ly/2MwsIL5>
2. ‘Investing to Save: The Economics of Increased Investment in Palliative Care in Australia,’ KPMG Australia, May 2020. [Noted in Media Watch 1 June 2020 (#668, p.5)] **Download/view report at:** <https://bit.ly/3d8DFL2>

Many people are not given the right care at the end of their lives

U.K. | *The House* – 23 February 2021 – Reform is needed if we’re to remove costly administrative hurdles and provide the palliative support that patients and their families so desperately need. During the pandemic, palliative care (PC) has come of age, putting patients foremost as they face the knife-edge of uncertainty between survival and death. During 2020, the demand for PC reached levels previously forecast for 2040. Rapidly, PC became an integrated core service across many hospitals, with outreach into care homes and the community. As deaths rose, PC professionals rapidly upskilled others in care of the dying, particularly in handling difficult conversations, and talking openly and sensitively about death with patients and families.

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Often, they are involved in staff support at every level. Amid all the black clouds of the pandemic, a few silver linings must guide our future care provision. Silos and bureaucracy have diminished as staff work across disciplines and specialties, seeking advice and recognising their own support needs. And despite the barriers of masks and personal protection equipment, people communicate more carefully and sensitively, showing compassion with their eyes and tone of voice to patients and relatives alike. But these staff are emotionally and intellectually exhausted. <http://bit.ly/3soEjv7>

End-of-life care must be improved

U.K. (Scotland) | *The Scotsman* (Glasgow) – 23 February 2021 – We have seen a substantial shift in people dying at home instead of hospital over the last year; over 4,000 more deaths at home in Scotland in 2020 than in previous years, which has largely been driven by the need to free up hospital beds for COVID-19 patients. We know that many people would prefer to die at home if possible, but it's unknown whether these terminally ill people, their families and carers were able to access and receive the care and support they needed during this time, as community services have been so stretched. Marie Curie and University of Edinburgh research recently projected that by 2040, two thirds of Scots could die at home, in a care home or a hospice. This is similar to what we have seen in 2020, thus we know what increased demand for support in the community and in care homes could look like in later years. Our most recent study has projected that by 2040, 95% of all people in Scotland who die may need a palliative care (PC) support, and over 40% will die from at least two conditions.¹ This could mean an additional 10,000 people dying with PC needs. <http://bit.ly/2NpbJes>

1. 'How many people will need palliative care in Scotland by 2040? A mixed-method study of projected palliative care need and recommendations for service delivery,' *BMJ Open*, published online 3 February 2021. [Noted in Media Watch 8 February 2021 (#703, p.7)] **Full text:** <http://bit.ly/39HdPyy>

N.B. Selected articles on PC in Scotland noted in Media Watch 8 February 2021 (#703, p.3).

Specialist Publications

Providing opportunities for patients to say more about their pain without overtly asking: A conversation analysis of doctors repeating patient answers in palliative care pain assessment

APPLIED LINGUISTICS | Online – 21 February 2021 – The authors' analysis has implications for how practitioners can repeat patient answers in a way that acknowledges what the patient says, and prompts, but does not obligate, the patient to elaborate. Firstly, the way the repeat is delivered is important. Repeating the patient's answer in a way that mirrors the patient's downward-final intonation (rather than adopting "questioning" intonation), and also mirrors the patient's prosodic rhythm, enable the repeat to be heard as displaying that the patient's description has been heard, and not problematically. Secondly, repeating patient answers is valuable at particular moments, such as following the introduction of new/revised pain matters, or when descriptions have been difficult to accomplish. In these moments it is particularly salient to encourage patients to check, or add to, their descriptions. The authors propose that recommendations to repeat patient answers include this more layered understanding of how

repeats function and when they are used. Previous research has shown that repeats have a wide range of functions, and the authors highlight the prosodic, lexical and epistemic features of a repeat which enable the doctor to simultaneously acknowledge what a patient has said, whilst creating an opportunity but not an obligation for the patient to expand upon or adjust their descriptions. Examining recordings of real-life clinical practice provides nuanced and situated understandings of how a linguistic technique, such as repeating a patient answer, actually works in clinical practice. **Full text:** <http://bit.ly/37F1j0Z>

Publishing Matters

'Beall's legacy in the battle against predatory publishers' (p.13), in *Learned Publishing*.

Cont.

Related:

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 February 2021 – ‘Including the spiritual dimension in multimodal pain therapy. Development and validation of the Spiritual Distress & Resources Questionnaire (SDRQ).’ Valid instruments for assessing spiritual resources and distress in pain therapy are scarce. The SDRQ was developed to fill this gap. The results from this study suggest that the SDRQ is an easy-to-use, reliable and valid screening instrument for assessing spiritual distress, spiritual resources and spiritual coping in patients with chronic pain. The SDRQ has the potential to be used with patients suffering from other chronic diseases and to disseminate the palliative approach to pain treatment to other areas of medicine. **Abstract (w. list of references):** <https://bit.ly/3aNNhfd>

Evaluating the integration of palliative care in national health systems: An indicator rating process with European Association for Palliative Care task force members to measure advanced palliative care development

BMC PALLIATIVE CARE | Online – 24 February 2021 – Palliative care (PC) development cannot only be assessed from a specialized provision perspective. Recently, PC integration into other health systems has been identified as a component of specialized development. Yet, there is a lack of indicators to assess PC integration for pediatrics, long-term care facilities, primary care, volunteering and cardiology. A process composed of a desk literature review, consultation and semi-structured interviews with Association task force members and a rating process was performed to create a list of indicators for the assessment of PC integration into pediatrics, long-term care facilities, primary care, cardiology, and volunteering. The new indicators were mapped onto the four domains of the WHO Public Health Strategy. A total of 34 new indicators were identified for national-level monitoring of PC integration. Ten were for pediatrics, five for primary care, six for long-term care facilities, seven for volunteering, and six for cardiology. All indicators mapped onto the WHO domains of policy and education while only pediatrics had an indicator that mapped onto the domain of services. Meaningful contributions are being made in Europe towards the integration of PC into the explored fields. These efforts should be assessed in future regional mapping studies using indicators to deliver a more complete picture of PC development. **Full text:** <http://bit.ly/3pORcqt>

“A silent epidemic of grief”

A survey of bereavement care provision in the U.K. and Ireland during the COVID-19 pandemic

BMJ OPEN | In print – Accessed 21 February 2021 – Changes to bereavement care practice were reported in: the use of telephone, video and other forms of remote support (90%); supporting people bereaved from non-COVID conditions (76%), from COVID-19 (65%), and people bereaved before the pandemic (61%); funeral arrangements (61%); identifying bereaved people who might need support (56%); managing complex forms of grief (48%) and access to specialist services (41%). Free-text responses demonstrated the complexities and scale of the impact on bereaved people and on health and social services, practitioners and their relationships with bereaved families. The pandemic has created major challenges for the support of bereaved people: increased needs for bereavement care, transition to remote forms of support, and the stresses experienced by practitioners, among others. The extent to which services are able to adapt, meet the escalating level of need and help to prevent a “tsunami of grief” remains to be seen. The pandemic has highlighted the need for bereavement care to be considered an integral part of health and social care provision. **Abstract:** <http://bit.ly/2NPDxhW>

N.B. Full study findings are yet to be submitted for publication in a peer-reviewed journal. See ‘Exceptional challenges of bereavement during the pandemic highlighted in interim findings,’ University of Bristol press release at: <https://bit.ly/37clUxy>

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Noted in Media Watch 30 November 2020 (#694, p.4):

- U.K. | *The Guardian* (London) – 26 November 2020 – ‘**U.K.’s COVID-19 bereaved suffer heightened grief, finds study.**’ Family and friends bereaved by COVID-19 experience “greatly increased negative experiences” and show higher grief and support needs compared to people suffering the loss of loved ones from other illnesses, researchers at Cardiff and Bristol universities found. They discovered COVID-19-bereaved people less likely to have been able to say goodbye to loved ones, less likely to have visited prior to death, and less likely to have had contact with friends and family after their bereavement. Researchers estimate 2.6 million people have been bereaved in the U.K. “at a time of profound disruption to our social support networks as well as intense pressure on health and social care.” <https://bit.ly/2V7WYqb>

Physicians’ views on the usefulness and feasibility of identifying and disclosing patients’ last phase of life: A focus group study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 22 February 2021 – The authors found that physicians consider it important and useful to prognosticate a patient’s last phase of life. In doing so, physicians are enabled to timely assess patients’ preferences for medical treatment and care in the last phase of life. The simply formulated surprise question (SQ) is considered a useful prognostic tool to facilitate prognostication. However, the assumed subjective character of the SQ may hamper its use. Clinical experience with patient and disease-related clinical factors are also facilitators of prognostication. Some studies have indeed found that clinical experience is associated with more accurate predictions of the last phase of life, but other studies found no such associations. The authors found that physicians supported the disclosure of the last phase of life (i.e., expected death within one year) as recommended in quality standards for palliative care, but they also stressed the importance of a gradual disclosure. Furthermore, the primary responsible physician, typically the

treating medical specialist, should initiate communication about the last phase of life with patients. However, apart from linking those discussions to moments of significant deterioration in patients’ health, little is known about the best way in which the last phase of life and patients’ wishes and preferences may be discussed. **Full text:** <http://bit.ly/3skmv4q>

Corrections & Clarifications

The *BMJ Supportive & Palliative Care* article, ‘The palliative and end-of-life care experiences, views and needs of Gypsy, Traveller and Roma communities: A systematic literature review and narrative synthesis,’ noted as ‘In print’ in Media Watch 15 February 2021 (#704, p.6), was retitled on publication 22 February 2021 as ‘Gypsy, Traveller and Roma experiences, views and needs in palliative and end-of-life care: A systematic literature review and narrative synthesis.’ **Abstract:** <https://bit.ly/3bFMqNk>

N.B. Search back issues of Media Watch for additional articles on the SQ at: <http://bit.ly/2ThijkC>

Clinical nurse specialist collaboration with a community-based palliative care program: An evidence-based practice project

CLINICAL NURSE SPECIALIST, 2021;35(2):88-95. Palliative care (PC) services are evolving from the inpatient setting to community-based models to meet the needs of patients in their homes. As community-based programs develop, healthcare systems are examining the various models of care. The evidence-based practice project evaluated a collaborative practice model between a clinical nurse specialist (CNS) and a community-based PC team. Quantitative analysis included 30-day readmissions and emergency department (ED) utilization in a pre-implementation and postimplementation design. The addition of a CNS did not significantly impact 30-day readmissions or ED visits. An unexpected outcome was that the CNS intervention was associated with an increase in social work visits. Results of focus groups suggested that the CNS improved care coordination, nursing support, education, and medical management. Both quantitative and qualitative analyses suggest that the CNS enhanced coordination of care and quality outcomes. **Abstract:** <https://bit.ly/3pPJEtW>

Advance care planning practices in the nursing home setting: A secondary analysis

THE GERONTOLOGIST | Online – 24 February 2021 – Advance care planning (ACP) is intended to support resident's preferences regarding health decisions, even when they can no longer participate. Little is known about the power discourses influencing how residents, family-members, and healthcare workers engage in ACP and how advance care directives are used if conflict arises. A large critical ethnographic study was conducted exploring decision-making when a resident's health deteriorates in the nursing home setting. ACP practices were not the focus of the original study, but the richness of the data warranted further exploration. A new research question was developed to inform a secondary analysis: How does ACP influence the relationship between resident values and clinical expertise when determining a direction of care at the time of a resident deterioration? A secondary analysis of data from an ethnographic study involving 184

hours of participatory observation, 40 semi-structured interviews and ACP policies and document review undertaken in two nursing homes in Melbourne, Australia. ACP may contribute towards a reductionist approach to decision-making. There is an urgent need for the development of evidence-based policy and legislation to support residents, families, and healthcare workers to make appropriate decisions, including withholding invasive treatment when a resident deteriorates. **Abstract:** <https://bit.ly/3bEKq7I>

Extract from *The Gerontologist* article

ACP may result in inaccurate documentation of residents' preferences and devalue clinical decision-making and communication with residents and family-members at the time of deterioration.

N.B. Selected articles on ACP in the nursing home setting, including long-term care facilities, noted in Media Watch 22 February 2021 (#705, pp.7-8).

Related:

- *NEJM CATALYST*, 2021;2(3). '**Supporting acute advance care planning with precise, timely mortality risk predictions.**' Leaders at New York University Langone Health determined that a system more precise than "not being surprised" by a patient's death in six months would give confidence to attending physicians in recognizing patients at the end of life and prioritizing advance care planning conversations accordingly. Replacing the standard "surprise question" with a three-tiered, artificial intelligence – enabled, electronic health record – integrated system has helped physicians identify a narrower, higher-risk population of hospitalized adults with a positive predictive value of 61% for two-month mortality. **Summary:** <https://bit.ly/3seald7>

COVID-19, promotion and provision of palliative care: Reaching out, accounting for linguistic diversity

GLOBAL HEALTH PROMOTION | Online – 24 February 2021 – The combined forces of economic globalization and international migration have resulted in specific challenges to palliative care (PC) systems. The COVID-19 pandemic has and is still greatly affecting elder populations as well as those across the age continuum living with long-standing chronic conditions or with pre-existing diverse unmet needs. While health promotion and PC may appear to be conceptually opposing fields, the authors argue that PC can and should fit under the umbrella of the health promotion continuum. This commentary discusses the importance of linguistic literacy and communication imperatives in the context of access to PC, given the broad, diversified and sensitive scope of care. While the pandemic has demonstrated that the public health responses of migrant host societies are deeply intertwined with policies as well as local rules and constraints, the promotion and provision of safe, timely and appropriate PC can be achieved through a sensitive assessment of differential contexts of diversity. The pandemic has painfully illustrated the need for a strong, respectful and equitable working partnership within the professions as well as with the civic society in order for the palliative needs of those exposed to a sustained risk not to be forgotten. **Full text:** <http://bit.ly/2ZVlfXZ>

Cont.

Related:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 February 2021 – ‘**Public messaging for serious illness care in the age of coronavirus disease: Cutting through misconceptions, mixed feelings, and distrust.**’ A year ago, the authors began a project designed to align public messages from 10 organizations involved in advance care planning (ACP), palliative care (PC), and hospice to increase public engagement. Their project plan was upended by the coronavirus disease 2019 (COVID-19) pandemic – but they used the opportunity to conduct focus groups during the pandemic that, compared with focus groups conducted before the pandemic, provide an important portrait of public perceptions of serious illness care that can be used to design for greater public engagement. **Abstract:** <https://bit.ly/3dRnbds>
- *NEJM CATALYST*, 2021;2(3). ‘**Conversing with high-risk patients to determine serious illness goals and values in the time of COVID-19.**’ Patients enrolled in the Integrated Care Management Program (iCMP) were contacted by their own nurse care coordinator for a serious illness conversation, discussing patients’ goals and values in the context of underlying illness and the threat of COVID-19. Simultaneously, nurses, medical students, and social care team members reached out to non-iCMP primary care patients identified as being at high risk of morbidity or mortality from COVID-19 and engaged these patients in conversations regarding healthcare proxy documentation and social determinants of health needs. **Full text:** <https://bit.ly/37zxzmq>

A leap of faith: Is there a formula for “trustworthy” AI?

THE HASTINGS REPORT | Online – 19 February 2021 – *Trust* is one of the big buzzwords in debates about the shaping of society, democracy, and emerging technologies. For example, one prominent idea put forward by the High-Level Expert Group on Artificial Intelligence appointed by the European Commission is that artificial intelligence (AI) should be trustworthy. In this essay, the authors explore the notion of trust and argue that both proponents and critics of trustworthy AI have flawed pictures of the nature of trust. They develop an approach to understanding trust in AI that does not conceive of trust merely as an accelerator for societal acceptance of AI technologies. Instead, the authors argue, trust is granted through leaps of faith. For this reason, trust remains precarious, fragile, and resistant to promotion through formulaic approaches. The authors further highlight the significance of *distrust* in societal deliberation, which is relevant to trust in various and intricate ways. Among the fruitful aspects of distrust is that it enables individuals to forgo technology if desired, to constrain its power, and to exercise meaningful human control. **Full text:** <https://bit.ly/2NODeO1>

Noted in Media Watch 21 September 2020 (#684, p.7):

- *HEALTH AFFAIRS* | Online – 16 September 2020 – ‘**Ethical considerations in the use of AI mortality predictions in the care of people with serious illness.**’ For patients who desire it, prognostic information should ideally help them make decisions about treatments, prepare for the future, and focus on their priorities. The use of automated artificial intelligence (AI) algorithms by palliative care teams ... to identify people approaching the end of life to prevent unwanted and non-beneficial care is an important goal. Because these people often incur high costs, reducing unwanted care can have the added benefit of lowering costs. Yet, despite AI’s potential, there is a need to address at least three core ethical issues before implementation of AI in this unique context. **Full text:** <https://bit.ly/3iBGGpP>

Noted in Media Watch 20 July 2020 (#675, p.3):

- *STAT* | Online – 15 July 2020 – ‘**An invisible hand: Patients aren’t being told about the AI systems advising their care.**’ At a growing number of prominent hospitals and clinics around the country, clinicians are turning to AI-powered decision support tools – many of them unproven – to help predict whether hospitalized patients are likely to develop complications or deteriorate, whether they’re at risk of readmission, and whether they’re likely to die soon. But these patients and their family members are often not informed about or asked to consent to the use of these tools in their care, a *STAT* examination has found. The result: Machines that are completely invisible to patients are increasingly guiding decision-making in the clinic. <https://bit.ly/3ezygwq>

Noted in Media Watch 6 July 2020 (#673, p.2):

- *STAT* | Online – 1 July 2020 – ‘**An experiment in end-of-life care: Tapping AI’s cold calculus to nudge the most human of conversations.**’ The daily email that arrived in physician Samantha Wang’s inbox ... contained a list of names and a warning: These patients are at high risk of dying within the next year. This list of names was generated by an algorithm that had reached its conclusions by scanning the patients’ medical records. The email was meant as a nudge, to encourage Wang to broach a delicate conversation with her patient about his goals, values, and wishes for his care should his condition worsen. A handful of hospitals and clinics around the country are deploying cutting-edge artificial intelligence models in palliative care. <https://bit.ly/38g2Auu>

Conflicts in the end-of-life care: Interviews with care staff by Buddhist priests and researchers

JAPANESE JOURNAL OF GERIATRICS, 2021;58(1):126-133. Interprofessional communication and collaboration is essential for a better end-of-life (EoL) and death, where individual dying people are respected and their satisfaction is the goal. The aim of this study was to explore: 1) Ethical conflicts viewed by care staff of geriatric institutions; 2) Their views about geriatric medicine; and, 3) Their views about religion in the context of institutional EoL care. Regarding ethical conflicts, six themes were merged: 1) Difficulty in knowing the will of the person being cared for; 2) Dissonance with the family; 3) Older person’s wish to die; 4) Losing the purpose for living; 5) Staff not being used to death; and, 6) Families not being used to death. Regarding geriatric medicine, eight themes were merged: 1) Gratitude for cooperation; 2) Persuasive explanation; 3) Not accepting death; 4) Not allowing patients to share a peer’s death; 5) Cold attitude; 6) Being drug therapy centered; 7) Not being person-centered; and, 8) Heavy burden for patients. Regarding religion, five themes were merged: 1) Expectation for salvation; 2) Barrier to hospitals; 3) Already involved in nursing homes; 4) Explicit religious traits are acceptable; and, 5) Favorable character of religious workers in institutions. **Full text (click on pdf icon):** <https://bit.ly/3aTZJdS>

N.B. Japanese language article.

A national survey of challenges faced by hospices [in the U.S.] during the opioid crisis: Estimates of pain medication shortages, missing medications, and opioids left in the home post-death

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 February 2021 – No national data exist on hospice medication shortages, the frequency that opioid medications go missing, and drug disposal practices. A national survey of 600 randomly selected hospices stratified by state and profit status was undertaken. Respondents were hospice representatives knowledgeable about agency policies and practices. Participants reported their knowledge and perceptions about medication shortages, frequency that opioid medications go missing, and the proportion of hospice deaths in which opioids are left in the home. 371 hospices completed surveys..., half (50%) of which were mid-sized (26-100 patients), and not-for-profit. Respondents had 7.5 years of agency experience. 42% of hospices – and 61% of large hospices – reported medication shortages. Among the full sample, 28% of agencies indicated shortages of morphine; 20% reported shortages of hydromorphone. Nearly half (43%) of hospice representatives reported that missing opioid medications occurred within the last 90 days. 52% of representatives reported employees are not allowed to dispose of medications after a home death; and, among home deaths, unused opioids were left in the home 32% of the time. This suggests opioid medications are frequently left in U.S. households after a hospice home death. Hospices face numerous challenges during the national opioid crisis. Interventions are needed to ensure access to needed treatments, mitigation of diversion, and safe medication disposal. **Abstract (w. list of references):** <https://bit.ly/3uEXOld>

N.B. Additional articles on medication diversion in hospices in the U.S. noted in Media Watch 30 April 2020 (#662, p.3) and 1 June 2020 (#668, p.14).

Search Back Issues of Media Watch @
<http://bit.ly/2ThijkC>

“Going home [is] just a feel-good idea with no structure”

A qualitative exploration of patient and family caregiver needs when transitioning from hospital to home in palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 22 February 2021 – Hospital-to-home transitions, particularly at the end of life, can be challenging for patients and their family caregivers. Therefore, there is a need to better understand gaps in expectations and experiences of these transitions. Theory can inform the creation of an intervention aimed at improving the hospital-to-home transition. Adults receiving inpatient palliative care (PC) who were being discharged to home-based PC, and their family caregivers, were recruited from two academic health centres in Toronto, Canada. Through examining the expectations and subsequent experiences of the transition, and exploring the gaps between them, the authors identified various transitions needs, health and well-being needs and practical needs (i.e., transportation, setting up the home for care, care providers in the home). Several enablers and disablers modified the likelihood of needs being met (e.g., caregiver role, education on symptom management, uncertainty, financial resources). The authors substantive grounded theory highlighted potentially measurable constructs that can be further tested. Future interventions should target the enablers/disablers to ensure health and well-being and practical needs are met in the transition. **Abstract (w. list of references):** <https://bit.ly/37CN7Wm>

N.B. Selected articles on “care transitions” noted in Media Watch 26 October 2020 (#689, pp.2-3), 28 September 2020 (#685, p.6), and 31 August 2020 (#681, pp.1-2).

Related:

- *PALLIATIVE MEDICINE* | Online – 23 February 2021 – ‘**Caring ahead: Mixed methods development of a questionnaire to measure caregiver preparedness for end of life with dementia.**’ New insight into indicators and core concepts of preparedness was gleaned through this study that helped to produce the ‘Caring Ahead’ questionnaire with current evidence for face and content validity. These findings should assist healthcare professionals and researchers to assess caregivers’ feelings of preparedness, identify caregivers in need of support, design and evaluate strategies aligned with a palliative approach. Future research is needed to evaluate questionnaire psychometrics (i.e., content, construct, predictive validity and reliability) in a larger sample and with different populations. **Full text:** <http://bit.ly/3qZfJR2>

A pilot study of the impact of virtually embodying a patient with a terminal illness

MEDICAL SCIENCE EDUCATOR | Online – 23 February 2021 – Compassionate end-of-life (EoL) care matters deeply for patients and their caregivers, but studies continue to demonstrate ways in which physicians fall short. Despite specific training during medical school, many patients report lack of empathy in their providers with respect to EoL conversations. This is likely because empathy is simply hard to teach. Numerous activities have been tried to combat the decline in empathy during medical training with little to moderate success. However, virtual reality, which allows users to viscerally experience anything from another person’s point of view, could be a game changer for building empathy within medicine. This type of perspective-taking has previously shown to improve understanding, reduce biases, facilitate empathy, and promote prosocial behaviors. In this pilot study ... first-year medical students were able to experience first-hand having a terminal illness, being told no further treatments are available and witnessing loved ones’ reactions. Data generated through surveys and reflections indicated a high level of place illusion, plausibility, and embodiment of users. This high level of immersion generated an increase in comfortability with talking about EoL issues, produced a better understanding of what patients and their families experience, and promoted a change in the way students would approach clinical skills. Analysis of reflections indicated a high level of empathy for the patient and his family members. **Abstract (w. list of references):** <https://bit.ly/3uxHMTi>

N.B. Additional articles on the potential role of VR in palliative and EoL care noted in Media Watch 22 February 2021 (#705, p.4):

Social difficulties in returning home for cancer patients in an early palliative situation: Prospective study in eastern Paris

MÉDICINE PALLIATIVE | Online – 23 February 2021 – Some cancer patients have a difficult social environment that affects their healthcare circuit and forbids them to return home safely. The aim of this prospective observational study is to determine the proportion of patients who felt they could not return home for social issues, the reasons for these difficulties, and their needs. The authors interviewed patients in an early palliative care situation about their social situation, in two oncology departments in eastern Paris. They also interviewed their doctor and caregivers about the situation of patients and their needs in terms of help and care. The number of patients unable to stay at home is significant and therefore a real problem. Finding new types of suitable housing for those patients seems essential to improve their quality of life. Moreover, the social support for cancer patients seems to be inadequate and needs to be improved. **Abstract:** <http://bit.ly/3kiiJ8T>

N.B. French language article.

Preparing nurses for palliative and end of life care: A survey of New Zealand nursing schools

NURSING EDUCATION TODAY | Online – 23 February 2021 – Nurses play a vital role in the care of people with advanced life-limiting illnesses, so palliative and end-of-life care (EoLC) is an essential skill nurses need to learn. Despite numerous reports in the international literature about educational developments in this area, there are widespread inconsistencies in undergraduate education, and graduates continue to report feeling unprepared for this part of their work. 13/18 (72%) educational institutions completed a national survey. All integrate palliative and EoLC in their teaching with an identified coordinator at 12 (92%) institutions. Formal teaching is provided at 11 (85%) institutions where lectures and tutorials are most common. Clinical placements with specialist palliative care (PC) providers are scarce and limited to senior students as elective placements. Assessment of student learning in palliative and EoLC is carried out at seven (54%) institutions, and formally evaluated at 12 (92%). Lack of teaching time and clinical placements with PC providers are barriers to increased learning opportunities in palliative and EoLC. This article provides comprehensive information about palliative and EoLC teaching in undergraduate nurse education in New Zealand. Teaching on this subject is not a mandatory requirement so there are inconsistencies in the teaching provided between educational institutions, and significant barriers to development. Mandatory competencies need to be introduced to ensure graduates have the knowledge, skills and attitudes required to provide optimal care for people near the end of life. **Abstract:** <http://bit.ly/3qRNTX6>

Citizens appreciate talking about death and learning end-of-life care: A mixed-methods study on views and experiences of 5,469 Last Aid Course participants

PROGRESS IN PALLIATIVE CARE | Online – 25 February 2021 – To the authors' knowledge, this is the first international multicentre study using a standardized public palliative care (PC) education program for citizens in different countries. The Last Aid Course is feasible on a large scale and was well accepted by the participants. Findings revealed that they found the atmosphere comfortable, instructors competent, and, they appreciated the course format, duration, topics and discussions about life and death. The combined results from quantitative and qualitative data show public PC education can be delivered using the Last Aid Course format in a very short time frame, within four teaching hours on a single day. **Full text (click on pdf icon):** <https://bit.ly/37OpcDx>

International Last Aid Conference

AIMS MEDICAL SCIENCE, 2021;8(1):42-45. The main topics of the October 2020 conference were the social impact of palliative care (PC), public PC education (PPCE), and experiences with Last Aid Courses from different countries. Invited lectures and submitted abstracts on these topics highlighted the need for PPCE. The experiences with Last Aid Courses for both adults and children, as well as the Online Last Aid courses that were developed during the COVID-19 pandemic, were presented. This conference report provides an overview of the topics and the content of the presentations: <http://bit.ly/2ZVTU9j>

Cont.

Noted in Media Watch 15 February 2021 (#704, p.12):

- *PUBLIC HEALTH* | Online – 5 February 2021 – ‘**First experiences with online Last Aid courses for public palliative care education during the COVID-19 pandemic.**’ The Last Aid course aims to teach public palliative care (PC) by increasing public awareness and empowering people about the role of the individual in the death of loved ones. COVID-19, however, has altered educational methods prohibiting classroom settings. Therefore, an online course was created to enable continued and safe public PC education. Findings of this mixed-methods study revealed overall course satisfaction for the online courses in line with previous findings for classroom teaching. The online platform enabled course participation from people previously unable or unwilling to attend... **Full text:** <http://bit.ly/3q9cSot>

Noted in Media Watch 4 February 2019 (#600, p.10):

- *HEALTHCARE* | Online – 28 January 2019 – ‘**Last Aid course. An education for all citizens and an ingredient of compassionate communities.**’ Knowledge in palliative care (PC) is very limited or totally absent in most communities, and information about the effects of educational procedures in teaching non-professionals in basic PC is sparse. In the Last Aid courses, the public knowledge approach and the initial experiences from the implementation process are described in this article. In addition, a review of the literature on educational efforts regarding PC for non-professionals and the existing literature on courses is provided. An international working group has established a curriculum for Last Aid courses based on four teaching hours (45 minutes each). **Full text:** <http://bit.ly/2Bem43h>

Exploring paramedics’ intention to use a specialist palliative care telehealth service

PROGRESS IN PALLIATIVE CARE | Online – 21 February 2021 – In a 12-month period, Ambulance Victoria (Australia) recorded 4,348 palliative related callouts, 70% resulting in hospitalisation. Paramedics throughout the world recognise the need for extra palliative care (PC) training or support. One solution is a specialist PC support telehealth service from palliative specialists (usually in tertiary hospitals) to paramedics on callouts to people with life-limiting illnesses. To maximise uptake and sustainability, it is prudent to examine factors that influence acceptance of such a service. In the current study, 112 paramedics employed by the Queensland Ambulance Service completed an online survey examining their Intention to Use the Specialist Palliative Care telehealth service as a function of the Technology Acceptance Model constructs (Perceived Usefulness, Perceived Ease of Use & Attitudes toward technology) and Palliative Care Self-Efficacy. A hierarchical multiple regression analysis demonstrated the predictive utility of Perceived Usefulness & Attitudes. Palliative Care Self-efficacy did not add any significant variance to the model. This research highlights the importance of addressing paramedics’ perceptions regarding the telehealth service and its usefulness when implementing a similar service model. **Abstract:** <https://bit.ly/3bxVrrH>

The role of ambulance services in reducing the gaps in access to end-of-life care: From conversations to policy

PROGRESS IN PALLIATIVE CARE | Online – 21 February 2021 – Reducing the gap between the need for and access to effective and best practice care at the end-of-life (EoL) is a goal of the Australian palliative care (PC) sector. Largely absent from the suite of plans, strategies and frameworks that map Australia’s path to quality EoL care for all patients is Palliative Care Australia the role of ambulance services. Instead, patients’ need for these services tends to be characterized as an undesirable consequence of an under-resourced PC sector and no longer necessary when the sector is fully resourced. The authors hypothesize that one reason for this characterization is that the ambulance and PC sectors have fundamentally different perspectives of EoL care. They conclude that further if the PC sector were to partner with ambulance services, the gap between the need for and access to EoL care would be reduced more rapidly and cost effectively. **Abstract:** <https://bit.ly/2NPoUVO>

N.B. Search back issues of Media Watch for additional articles on the role of paramedics in palliative and end-of-life care at: <http://bit.ly/2ThijkC>

“Cured” but not “healed”

The application of principles of palliative care to cancer survivorship

SOCIAL SCIENCE & MEDICINE | Online – 25 February 2021 – Application of principles of palliative care (PC) to the concept of survivorship may serve to establish an interdisciplinary approach to guide those treated for cancer through the experience of being “cured” but not “healed.” Valuable lessons may be garnered from PC if its principles are considered within the context of survivorship. The authors define key terms including cured, healed, survivorship, and quality of life (QoL) and delineate the central tenets of PC and disease-modifying care. Since pursuit of a cure tends to dominate provision of oncological care, Western society’s prevailing death denying attitudes often equate to the prioritization of advanced medical treatment to postpone death. Accordingly, the “modern paradox” of medicine is examined in consideration of the suffering that often results from advanced medical treatment that is intended to alleviate the cause of suffering and ultimately “deny” death. However, owing to the profound consequences of advanced medical treatment and the associated losses of function concomitant with cancer, there is an apparent need for a framework of care that attends to these survivorship issues. When the experience of being cured but not healed is articulated through a theoretical discussion of liminality and the “remission society,” the applicability of PC to survivorship care becomes apparent. By embracing principles of PC, survivorship care may be guided by a theoretical foundation that provides cancer survivors with care that supports increased QoL, biopsychosocial symptom management, and a holistic perspective of the illness experience. Accordingly, application of PC to survivorship may establish congruence between notions of cured and healed. **Abstract:** <http://bit.ly/3pStgZD>

Publishing Matters

Beall’s legacy in the battle against predatory publishers

LEARNED PUBLISHING | Online – 18 February 2021 – Between 2009 and 2012, Jeffrey Beall published four articles which analysed 18 publishers (17 of which he identified as predatory). He also introduced the term “predatory” in the context of scientific publishing. In 2012, he started Beall’s List, which maintained a list of predatory publishers and journals. This became a valuable resource for those who wanted to know if a journal was legitimate, although others were very critical of the list. This article considers what he wrote and the list he developed and the criticisms that have been levelled against Beall’s list. Beall’s legacy can be considered to ensure that the problems of fraudulent or inappropriate publishing practices are highlighted and that the scientific community remains aware of the problem. Unfortunately, his legacy has not led to an eradication of predatory journals, and the problem appears to have become worse in the past decade. Although there is opportunity to build on his legacy, there have been few practical moves, and this article suggests that there is an opportunity for clearer, more universally accepted guidelines and approval criteria for quality journals. **Abstract:** <https://bit.ly/3snr1in>

N.B. Beall’s ‘List of Potential Predatory Journals & Publishers’: <http://bit.ly/3pQ8Foz>

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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://bit.ly/2RPJy9b>

Noted in Media Watch 14 September 2020 (#685, p.12):

- *JOURNAL OF ACADEMIC LIBRARIANSHIP*, 2020;46(6):102236. '**A qualitative content analysis of watchlists vs safelists: How do they address the issue of predatory publishing?**' Predatory journals and publishers are a growing concern in the scholarly publishing arena. As one type of attempt to address this increasingly important issue, numerous individuals, associations, and companies have begun curating journal watchlists or journal safelists. This study uses a qualitative content analysis to explore the inclusion/exclusion criteria stated by scholarly publishing journal watchlists and safelists to better understand the content of these lists, as well as the larger controversies that continue to surround the phenomenon that has come to be known as predatory publishing. **Full text:** <https://bit.ly/3m9pNoF>

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International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/3q2Jlgb>

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Asia



Asia Pacific
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ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2SWdYWP>

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Australia

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

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

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/3EPKUAC>

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

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

South America

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

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Something Missed or Overlooked?

IF YOU ARE AWARE OF A CURRENT REPORT, ARTICLE, ETC., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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