

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

The myriad consequences of the COVID-19 crisis have illuminated several important aspects of the delivery of high-quality critical care, including the need for palliative care integration across all care settings amid this public health emergency.

'Increasing critical care nurse engagement of palliative care during the COVID-19 pandemic' (p.9), in *Critical Care Nurse*.

Canada

Compassionate care act becomes law in Ontario

ONTARIO | Canadian Society of Palliative Care Physicians – 1 December 2020 – Ontario Bill 3, an 'Act providing for the development of a provincial framework on palliative care,' passed third reading in the Ontario legislature and will become law. The purpose of the Act is to develop a framework to ensure that every Ontarian has access to quality palliative care (PC). The Act requires the Minister of Health to develop a provincial framework designed to support improved access to PC. The Minister must table a report setting out the provincial framework in the Legislative Assembly within one year after the Bill comes into force. Within three years after the report is tabled, the Minister must prepare and table a report on the state PC in Ontario. Each report must be published on a Government of Ontario website. Passing of the law sets a positive precedent for

other provinces and shows demonstrate provincial government support for PC. The Bill was supported by 40 stakeholders, including Canadian Society of Palliative Care Physicians, Canadian Cancer Society, Canadian Hospice Palliative Care Association, ALS Canada, and health professionals from across the province. **Download/view Bill 3 at:** <https://bit.ly/3mMDhGU>

Specialist Publications

'**Serious illness conversation-evaluation exercise: A novel assessment tool for residents leading serious illness conversations**' (p.13), in *Palliative Medicine Reports*.



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.14.

U.S.A.

Referral management the biggest obstacle to palliative care growth

HOSPICE NEWS | Online – 30 November 2020 – Hospices that provide palliative care (PC) have found that issues surrounding referral management were the most significant hindrance to the financial stability of their programs, according research conducted by the National Hospice & Palliative Care Organization.¹ Close to 50% of a statistically significant sample of 328 providers indicated in a survey that referral management was their biggest concern, citing issues such as a lack of understanding of PC among clinicians in other settings as well as among patients and families. Both of these issues contribute to troubles maintaining adequate referral volumes. Providers and other stakeholders have their work cut out for them when it comes to raising awareness and understanding of PC. A *Journal of Palliative Medicine* study found that as many as 71% of people in the U.S. have little to no understanding of what PC is, including many clinicians in a position to refer patients to PC or hospice.² Roughly half of community-based palliative care (PC) providers in the U.S. are hospices, according to the Center to Advance Palliative Care.³ While a growing number of hospices are diversifying their service lines to include PC, many struggle to maintain financial sustainability in the current payment environment, which most prevalently relies on Medicare fee-for-service models. <https://bit.ly/2Vn86Gg>

Extract from *Hospice News* article

While no standardized definition exists for “palliative care,” the U.S. Centers for Medicare & Medicaid (CMS) Services defines the term as “patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. PC throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.”
Download/view CMS definition at: <https://bit.ly/3lrDHRm>

1. ‘National Hospice & Palliative Care Organization Palliative Care Needs Survey Results: Summary,’ November 2020. [Noted in Media Watch 30 November 2020 (#694, p.2)] **Download/view at:** <https://bit.ly/2Hundo>
2. ‘Awareness of palliative care among a nationally representative sample of U.S. adults,’ *Journal of Palliative Medicine*, published online 30 April 2019. [Noted in Media Watch 6 May 2019 (#613, p.9)] **Abstract:** <http://bit.ly/2UT2Ozi>
3. ‘Mapping community palliative care: A snapshot,’ Center to Advance Palliative Care, New York City, New York, December 2019. [Noted in Media Watch 23 December 2019 (#645, p.3)] **Down-load/view at:** <http://bit.ly/2tswrzB>

Related:

- *HOSPICE NEWS* | Online – 4 December 2020 – ‘**U.S. ranks low in palliative care duration.**’ The average length that patients receive palliative care (PC) in the U.S. is lower than in other countries, a recent study reported.¹ Much of the nation remains underserved despite rising demand, with limited payment opportunities restricting growth. This disparity indicates a growing need to address barriers and inequities in access, with funding playing a large role in the U.S.’s lag. The study’s findings suggest that the nation’s payment structure for PC, typically through Medicare fee-for-service programs, may be a contributing factor. The requirement that patients must forgo curative treatment in order to receive hospice care could also play a role, according to this new research. <https://bit.ly/2JV2wbG>
1. ‘Duration of palliative care before death in international routine practice: A systematic review and meta-analysis’ *BMC Medicine*, published online 26 November 2020. [Noted in Media Watch 30 November 2020 (#694, p.6)] **Full text:** <https://bit.ly/3mfMdo8>

COVID-19 surge pummeling hospice operations, finances

HOSPICE NEWS | Online – 29 November 2020 – A strained workforce and patient accessibility continue to plague hospice providers nearly a year into the COVID-19 pandemic. The recent uptick of cases has further pressed hospice providers, with concerns growing about their ability to respond as the year comes to a close. Another surge of the pandemic is hitting the U.S. almost 11 months following the initial federal emergency declaration, with the U.S. Centers for Disease Control & Prevention reporting nearly new 1.2 million cases in the last week alone. Balancing staff scheduling needs with increased demand for hospice and palliative care has pressed providers during the pandemic. Staff burnout has forced many hospices to re-evaluate their policies around paid leave/paid time off as employees respond to childcare needs with school closures and remote learning, as well as falling ill to the virus themselves or quarantining after possible exposure. Limited availability and rising costs of personal protective equipment challenged hospices in their ability to maintain and support a healthy workforce in the early days of COVID-19. Competition for these resources has since improved, but the upswing of cases has led to unease about continued availability. <https://bit.ly/2Jnc3YK>

Noted in Media Watch 2 November 2020 (#690, p.15):

- *PUBLIC HEALTH NURSING* | Online – 27 October 2020 – ‘**The impact of COVID-19 on the hospice and palliative care workforce.**’ The findings of this cross-sectional survey suggest that the COVID-19 pandemic has strained the palliative and hospice care workforce as it provides increased services at an unprecedented rate to patients and families. The implications of these findings are important for public health nurses who are skilled in disaster management and quickly respond to emergencies. The expertise of public health nurses can be leveraged to support palliative care (PC) agencies as they strive to manage the pandemic in the communities they serve. Most survey respondents (70%) reported an increase in specific PC services as a result of the pandemic. **Abstract:** <https://bit.ly/37KEvhj>

Noted in Media Watch 3 August 2020 (#677, p.7):

- *PALLIATIVE MEDICINE* | Online – 31 July 2020 – ‘**Prioritising workforce wellbeing and resilience: What COVID-19 is reminding us about self-care and staff support.**’ The physical and psychosocial suffering associated with the impact of the COVID-19 pandemic has brought unprecedented operational and ethical challenges for palliative care (PC) providers, bringing workforce considerations into sharp focus. To maintain the provision of quality PC in the wake of such challenges, there is a clear need to prioritise wellbeing and resilience in the PC workforce. It has also been important to offer such opportunities to the broader health workforce who also have been plunged into a steep learning curve to provide PC, outside their usual scope of clinical practice. **Full text:** <https://bit.ly/3k2SNNJ>

Specialist Publications

‘**Palliative care in critically ill COVID-19 patients: The early New York City experience**’ (p.9), in *BMJ Supportive & Palliative Care*.

‘**A comprehensive approach to palliative care during the coronavirus pandemic**’ (p.9), in *Journal of Palliative Medicine*.

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>



International

Palliative Care and COVID-19: Grief, Bereavement and Mental Health

AUSTRALIA | Palliative Care Australia – 4 December 2020 – The association’s new outcomes paper provides recommendations for policymakers, health and aged care leaders and professionals, and consumers and carers to meet the mental health, grief and bereavement needs of Australians during the current pandemic and any future pandemics or disasters. As part of its planning and leadership for the palliative care (PC) sector during the COVID-19 pandemic, the association held two strategic forums in 2020 with experts in PC, grief, bereavement and mental health to identify the emerging issues, available resources and gaps in current service provision. The outcomes paper summarises the key outcomes of these two strategic meetings together with key research to identify the immediate and longer term issues which will have ongoing impact in the Australian community. Reflecting on the consequences of the COVID-19 pandemic and investing in strategic solutions will ensure that Australia is well equipped to manage the grief, bereavement and mental health challenges ahead. **Download/view report at:** <https://bit.ly/2L8nX9H>

Specialist Publications

‘What exactly is “complicated” grief? A scoping research literature review to understand its risk factors and prevalence’ (p.12), in *Omega – Journal of Death & Dying*.

‘The prevalence of childhood bereavement in Scotland and its relationship with disadvantage: The significance of a public health approach to death, dying and bereavement’ (p.12), in *Palliative Care & Social Health Practice*.

“Do not resuscitate” orders caused potentially avoidable deaths, regulator finds

U.K. (England) | *The Guardian* (London) – 3 December 2020 – Do-not-resuscitate orders were wrongly allocated to some care home residents during the COVID-19 pandemic, causing potentially avoidable deaths, the first phase of a review by England’s Care Quality Commission (CQC) has found.¹ The regulator warned that some of the “inappropriate” do not attempt cardiopulmonary resuscitation (DNACPR) notices applied in the spring may still be in place and called on all care providers to check with the person concerned that they consent. The review was prompted by concerns about the blanket application of the orders in care homes in the early part of the pandemic, amid then prevalent fears that National Health Service hospitals would be overwhelmed. The CQC received 40 submissions from the public, mostly about DNACPR orders that had been put in place without consulting with the person or their family. These included reports of all the residents of one care home being given a DNACPR notice, and of the notices routinely being applied to anyone infected with COVID-19. Some people reported that they did not even know a DNACPR order had been placed on their relative until they were quite unwell. DNACPR decisions can be made by a consultant, GP or suitably qualified nurse and should be made in consultation with the person concerned. They are a common part of end-of-life care, not least because CPR is an invasive and traumatic medical intervention and is mostly unsuccessful, saving fewer than 10% of people outside of hospital settings. But such notices should not be issued in a blanket form, the CQC said. <https://bit.ly/3lBb6cG>

1. ‘CQC finds that combination of increasing pressures and rapidly developing guidance may have contributed to inappropriate advance care decisions,’ Care Quality Commission (press release), December 2020: <https://bit.ly/3mC7NTV>

Dying in the time of coronavirus: Hospices face impossible decisions as end-of-life care is changed by the pandemic

EUROPE | *Politico* (Brussels, Belgium) – 30 November 2020 – Governments acknowledge that those who are dying need contact with their loved ones – and have specifically written exemptions on visiting into legislation. But it’s not government guidelines that have had to shape policy at local hospices. Instead, area restrictions, case levels and outbreaks at the hospices themselves have forced institutions to make impossible decisions on who can see their loved one in the last few days of their life, and who cannot. Leena

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Pelttari, Chief Executive Officer of Hospice Austria, said that while the separation may be hard for patients, it's "even harder" for family and friends. Max Watson, director of Project ECHO at Hospice UK and consultant in palliative medicine in the Western Trust in Northern Ireland, agrees. "In some ways, the burden has been highest for families, who feel awful guilt and responsibility for being separated," he said. "They're trying to help their loved one, be with them, support them." Volunteering in palliative care (PC) has also taken a knock. Chiara Francesca Caraffa, the general manager of the Italian volunteers organization Presenza Amica and board member of the Italian Federation for Palliative Care, said in-person volunteering came to a complete halt at the start of the pandemic. Even in the second wave in Italy, volunteers are still navigating video calls to support those dying. The effect of dying alone during the pandemic is difficult to quantify. Much of the research has focused on those with COVID-19 dying in hospitals and care homes,¹ with little work yet published on the more general impact on PC for those without coronavirus. There also isn't data yet available to determine whether those with limited visitors are dying sooner than they would under more normal circumstances. <https://politi.co/3qiaAUJ>

1. 'Dying from Covid-19: Loneliness, end-of-life discussions and support for patients and their families in nursing homes and hospitals. A national register study.,' *Journal Pain & Symptom Management*, published online 25 July 2020. [Noted in Media Watch 27 July 2020 (#676, p.4)] **Full text:** <https://bit.ly/2BvcXP7>

Watchdog criticises refusal to allow prisoner to die in a hospice

IRELAND | *The Irish Examiner* (Blackpool, Cork) – 28 November 2020 – A state watchdog has expressed concern at the rejection by the Irish Prison Service of several of its recommendations following an investigation into the death of a terminally ill prisoner. He was refused compassionate temporary release to allow him to die in a hospice. The Inspector of Prisons, Patricia Gilheaney, said the decision to refuse compassionate release [even though a hospice bed was available] was contrary to the advice of medical staff and was also "at odds" with the view of the prison's management and pastoral team, who believed the appropriate setting to provide end-of-life care was in a hospice. "A prison cell cannot be equated to a hospital or hospice setting," said Ms. Gilheaney, in a report into the death of a 56-year-old prisoner¹ – identified only as Mr. O – at the Midlands Prison in Portlaoise on 30 October 2018. It is the second report published this year by the Inspector of Prisons that highlighted how a terminally ill prisoner had died in their cell at the Midlands Prison, when a hospice setting had been recommended by medical staff. <https://bit.ly/3qaHC8O>

1. 'Investigation Report into the circumstances surrounding the death of Mr. O 2018, aged 56, at the Midlands Prison on 30 October 2018,' Office of the Inspector of Prisons, November 2020. **Download/view report at:** <https://bit.ly/39pmYMk>

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report, can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Extract from Ireland's Office of Inspector of Prisons report

An investigation into the circumstances that surrounded the death of Mr. O included the following observation/recommendation: "End-of-life care for prisoners is not a frequent occurrence. It is recommended that the decision-maker in each case should visit and speak directly with the prisoner concerned, relevant medical, nursing and other healthcare personnel providing care and treatment in the prison and also prison management and chaplaincy." The Irish Prison Service did not accept this recommendation. **Download/view report at:** <https://bit.ly/3ll3MBR>

New report finds "compassionate communities" resilient but under-resourced

AUSTRALIA (New South Wales) | *Mirage News* (Wollongong) – 27 November 2020 – Researchers from Western Sydney University in partnership with The GroundSwell Project, have released a new report, the first comprehensive assessment of community-centred end of life care in Australia.¹ The University's Caring

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at End of Life research team documented the experiences of people from nine compassionate community projects across Australia over a two-year period, highlighting the challenges and benefits of this model of care. “Compassionate Communities are a relatively new way of providing palliative care. Through a social network, responsibilities are divided to ensure people with life-threatening or life-limiting conditions receive the care they want and need,” said Professor Debbie Horsfall. “The report documented the barriers that exist to delivering this type of care, and the strategies being employed to overcome them. By utilising the knowledge of these communities, and insights from the international community, we can better support and develop compassionate communities in Australia.” Following focus groups and interviews with key stakeholders, the comprehensive report made several recommendations. These include: 1) Develop an easy-to-use process of documentation for workers in this field to provide evidence of lived experiences, using stories and narratives as evidence; 2) Develop resources that showcase diverse examples of how the work can be done; 3) Support and expect a “whole of community” response and re-presentation; and, 4) Develop and model collective and dispersed leadership. An urgent need for funding was also identified to provide structured support and practitioner-focused resources. The report also suggests that communities who are well placed to develop compassionate communities receive support as a priority. <https://bit.ly/2JnW38U>

1. ‘Researching Compassionate Communities in Australia: A short-term longitudinal study,’ November 2020. **Download/view at The GroundSwell Project website:** <https://bit.ly/2JlvjGg>

Noted in Media Watch 4 February 2019 (#600, p.9):

- *HEALTH PROMOTION INTERNATIONAL*, 2020;35(1):160-170. ‘**Unpacking “the cloud”: A framework for implementing public health approaches to palliative care.**’ The Health Impact Change Model (HICM) was developed to unpack the complexities associated with the implementation and evaluation of a Canadian compassionate communities intervention. The HICM offers utility for citizens, leaders and decision-makers who are engaged in the implementation of population health level strategies or other social approaches to care, such as compassionate cities and age or dementia-friendly communities. The HICM’s concepts can be adapted to address a community’s healthcare context, needs, and goals for change. **Abstract:** <http://bit.ly/2RrPggd>

N.B. Selected articles on public health approaches to palliative care noted in Media Watch 28 September 2020 (#685, pp.14-15).

Specialist Publications

Lessons on older LGBTQ individuals’ sexuality and spirituality for hospice and palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 December 2020 – Hospice and palliative care (PC) are in the beginning stages of providing inclusive care to older lesbian, gay, bisexual, transgender, queer (LGBTQ) patients. This inclusivity is exceedingly more pressing given the growing population of out and aging LGBTQ individuals. Hospice and palliative literature recognizes that spirituality and religion can be fraught topics for LGBTQ patients. A few resources are available to help providers give more inclusive care. Few in hospice and PC, however, explicitly outline the direct connection for LGBTQ elders between their sexuality and their spiritual lives. Keeping with the tradition of critical theory, participants in this study were asked “is there a connection for you between your

sexuality and your spirituality? if so, what?” The participants expanded on this connection using five themes in their answers: 1) The sexual act itself is spiritual; 2) Their authentic LGBTQ journey as spiritual; 3) Love/attraction is spiritual; 4) Spirituality and sexuality are inseparable; and, 5) Noting the ineffability of the sexuality-spirituality connection. **Abstract (w. list of references):** <https://bit.ly/33Gkt4x>

Publishing Matters

‘**Predatory nursing journals: A case study of author prevalence and characteristics**’ (p.13), in *Nursing Ethics*.

N.B. Additional articles on hospice and PC for LGBTQ people noted in Media Watch 2 November 2020 (#690, pp.1-2).

Are we getting what we really want? A systematic review of concordance between Physician Orders for Life-Sustaining Treatment (POLST) documentation and subsequent care delivered at end of life

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 November 2020 – With an increased utilization of the POLST paradigm in various healthcare settings along with continued dissemination across the nation, it is critical to examine whether documented wishes on POLST are concordant with subsequent care delivered. Of 1,406 articles identified in this systematic review, 10 articles met the authors' inclusion criteria. Together, included studies represent 5,688 POLST forms reviewed from individuals residing in a total of 126 nursing care facilities, 9 elderly care centers, 4 community settings, and 2 hospitals. Preference for cardiopulmonary resuscitation and actual delivery/withholding of resuscitation was the most observed intervention in study of concordance. It is also where highest concordance rate (97.5%) was reported. Seven studies compared care provided during end of life (EoL) and the level of medical intervention requested on POLST forms (91.17% concordance). Preference to use artificial nutrition/ hydration, and actual delivery was 93.0%, and antibiotics use preference and delivery was 96.5% (reported in 4 studies). Published literature evidence suggests that EoL care wishes documented on POLST forms were largely concordant with subsequent care delivered. Additional research is needed to evaluate concordance between POLST documentation and care received among POLST users, who experienced multiple care transitions across healthcare settings, or across state during EoL care journey. **Abstract (w. list of references):** <https://bit.ly/3o8J0au>

Noted in Media Watch 21 September 2020 (#684, p.9):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 16 September 2020 – ‘**Conflicting orders in Physician Orders for Life-Sustaining Treatment forms.**’ This study characterizes the prevalence and predictors of Physician Orders for Life-Sustaining Treatment (POLST) documentation with conflicting orders. 3,123 POLST users with chronic life-limiting illness who died between 2010 and 2015 participated. Although most POLSTs are actionable by clinicians, 5% had conflicting orders for cardiac arrest and medical interventions, and 24% had one or more conflicts between orders for cardiac arrest, medical interventions, antibiotics, and artificial nutrition. These conflicting orders make implementation of POLST challenging for clinicians in acute care settings. **Abstract:** <https://bit.ly/2RwF9pk>

Noted in Media Watch 24 February 2020 (#654, p.7):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 16 February 2020 – ‘**Association of Physician Orders for Life-Sustaining Treatment with ICU admissions among patients hospitalized near the end of life.**’ For patients with Physician Orders for Life-Sustaining Treatment (POLST) documentation hospitalized near the end of life, how often is their inpatient care consistent with POLST-ordered limitations? Among patients with POLSTs and with chronic life-limiting illness who were hospitalized within 6 months of death, treatment-limiting POLSTs were significantly associated with lower rates of ICU admission compared with full-treatment POLSTs. However, 38% of patients with treatment-limiting POLSTs received intensive care discordant with their POLST. **Full text:** <http://bit.ly/2vBe6RX>

Socially situated brain death

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2020;22(12):E981-1070. In 1980, the U.S. Uniform Determination of Death Act (UDDA) defined death as “(1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem ... in accordance with accepted medical standards.” Interpreting the UDDA definition and applying neurological criteria for diagnosing brain death sound straightforward. Brain death is, however, socially situated, not observer independent, and fraught with uncertainty and ambiguity. This issue of the journal investigates some of the ethical, cultural, and legal complexities of one of medicine's most critical tasks: being sharp and sure about who is alive and who is dead. **Journal contents page:** <https://bit.ly/2HYbjJd>



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Experiences with the Liverpool Care Pathway for the dying patient in nursing home residents: A mixed-method study to assess physicians' and nurse practitioners' perceptions

BMC PALLIATIVE CARE | Online – 30 November 2020 – The Liverpool Care Pathway for the dying patient (LCP) is a multidisciplinary tool developed for the dying phase for use in palliative care (PC) settings. The literature reports divergent experiences with its application in a nursing home setting related to its implementation and staff competencies. This mixed-methods study with 159 survey respondents and ten interviews provides an understanding of how the LCP is being used and experienced in practice for nursing home residents, including those with dementia. Those responsible for (medical) care perceived an instrument that prompts regular assessment of a dying person as contributing to good care. As such, the LCP was valued, but there was a clear need to start it earlier than in the last days or hours of life—perhaps related to many residents having dementia. There was also a need for a shorter version and for integration of the LCP in the electronic health record. Such regular assessments with an instrument that focusses on quality of care and good symptom control can improve PC for nursing home residents with and without dementia.

Full text: <https://bit.ly/2JsqlaC>

Noted in Media Watch 16 November 2020 (#692, p.10):

- **WELLCOME OPEN RESEARCH** | Online – 27 October 2020 – ‘**International transfer and translation of an end-of-life care intervention: The case of the Liverpool Care Pathway for the dying patient.**’ The authors explore how and why the Liverpool Care Pathway (LCP) for the dying patient was transferred to 20 countries beyond the U.K., and with what consequences for policy and practice. This article synthesises findings from 95 publications contained in a historical narrative literature review on the implementation of the LCP outside the U.K. The authors explore the timelines and patterns of development and implementation in the specific countries, to consider what forms of research and evaluation about the LCP were undertaken to establish its effectiveness... **Full text:** <https://bit.ly/3lbEWoz>

N.B. Additional articles on the LCP noted in Media Watch 10 February 2020 (#652, p.13) and 13 July 2020 (#674, p.7).

Unmet spiritual needs in palliative care: Psychometrics of a screening checklist

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 1 December 2020 – While studies in palliative care (PC) use measures of spirituality and religious belief, there have been few validation studies of a screening tool that identifies unmet spiritual needs. A multidisciplinary research team developed and examined the usefulness, reliability and validity of a 17-item Spiritual Concerns Checklist (SCC) as a screening tool for unmet spiritual needs. A cohort of patients recruited from three PC services in Sydney and Melbourne, Australia completed anonymous questionnaires. Among 261 patients, while only 15% directly sought spiritual care, nearly 62% identified at least one spiritual concern. Existential needs (fear of the dying process 32%; loss of control 31%), regret (20%), need for forgiveness (17%), guilt (13%), loss of hope (13%) and meaning (15%) were prominent concerns. Eleven concerns were present for more than 10% of the participants and 25% of religiously orientated participants expressed concerns. This preliminary analysis of the newly developed SCC demonstrated its usefulness, reliability and validity. The findings of this study encourage refinement and ongoing development of the SCC with further investigation of its psychometric properties in varying populations. **Abstract:** <https://bit.ly/39xWKqU>

Noted in Media Watch 16 March 2020 (#657, p.11):

- *KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE*, 2020;23(1):1-4. ‘**Initial spiritual screening and assessment: Five things to remember.**’ This article presents five things that PC nurses can consider in order to improve their spiritual screening and assessment practices: 1) Understand that spirituality is manifest in a myriad of ways and is not the same thing as religiosity; 2) Screen for spiritual distress, and then later conduct a spiritual history or assessment; 3) Remember that spirituality is not just something to assess upon admission; 4) Know that there are many ways to assess spirituality (it is not merely how a patient verbally responds to a question about spirituality or religiosity; and, 5) Remember that assessment can also be therapeutic. **Full text (click on pdf icon):** <http://bit.ly/39PAjuZ>

Increasing critical care nurse engagement of palliative care during the COVID-19 pandemic

CRITICAL CARE NURSE | Online – 1 December 2020 – The COVID-19 pandemic has made explicit the need for palliative care (PC) integration throughout settings in hospitals and communities worldwide as the suffering of patients and families is exacerbated. The authors call for PC integration throughout the practice of high-quality critical care to ensure the holistic needs of patients and families are met in these uncertain times. Achieving this ideal will require leadership, advocacy, persistence, and a rapid shift in perspectives and protocols. PC is critical care; and critical care nurses are ideally positioned to ensure this congruence is realized, disseminated, and empathically translated into practice toward improved quality outcomes and person-centered care. **Full text:** <https://bit.ly/3g0EBmN>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 2 December 2020 – ‘**Palliative care in critically ill COVID-19 patients: The early New York City experience.**’ This study ... highlights the differences in patients who did and did not receive palliative care (PC) services during their stay. Patients who did receive PC in this cohort were generally older, sicker and required mechanical ventilation. Unfortunately, almost two-thirds of patients admitted to the ICU did not have a PC consult. Similarly, among patients that ultimately died, PC was involved in slightly over half of the cases. The lack of deployment of PC services in the ICU further supports previous studies highlighting an under utilisation of PC services in this patient population. **Full text:** <https://bit.ly/2Vwsgxt>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 December 2020 – ‘**A comprehensive approach to palliative care during the coronavirus pandemic.**’ In preparation for a potential second surge of COVID-19 in New York City in fall 2020, the authors created a surge plan that leverages and adapts many of the models used in the initial wave in the spring. Their comprehensive response successfully expanded the palliative care (PC) team’s reach and, at the height of the pandemic, allowed their teams to meet the increased demand for PC consults. Feedback and preliminary data suggest that virtual outpatient visits, embedded staff, hospice units, and team expansion through training other disciplines and deploying ePalliative Care services were impactful interventions. **Full text:** <https://bit.ly/2VBGKft>

Would people living with epilepsy benefit from palliative care?

EPILEPSY & BEHAVIOUR | Online – 24 November 2020 – Despite the recent growth of the field of neuropalliative care there has been scant attention paid to the relevance of palliative care (PC) principles in epilepsy or the potential for PC approaches to improve outcomes for persons living with epilepsy and their families. This has been a significant oversight. PC may provide a useful framework for addressing the many sources of suffering facing persons living with epilepsy, for engaging patients and families in challenging conversations, and to focus efforts to improve models of care for this population. The authors review areas of significant unmet needs where a PC approach may improve patient and family-centered outcomes, including complex symptom management, goals-of-care, advance care planning, psychosocial support for patient and family and spiritual well-being. They highlight areas where epilepsy patients may have unique PC needs compared to other patient populations and conclude with suggestions for future research, clinical, and educational efforts. **Abstract (w. list of references):** <https://bit.ly/3qgBFqS>

N.B. Selected articles on neuropalliative care noted in Media Watch 20 July 2020 (#675, p.9).

Rethinking the protection of vulnerable groups in the pandemic situation (SARS-COVID 19): The necessity of implementing the Human Rights Act and Human Security Framework into the healthcare professionals and (non)medical caregivers

EUROPEAN RESEARCH STUDIES JOURNAL, 2020;Special Issue:1138-1143. Changes caused by the COVID-19 pandemic in the organization of medical care and medical social work provided to patients as part of end-of-life care (EoLC) make it necessary to re-evaluate the ethical and legal obligations protection of this particularly vulnerable group. This article draws attention to palliative care, a specific form of medical

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care, and in particular, EoLC. Changes in medical practice and medical social work caused by the pandemic, while epidemiologically justified, in many cases lead to violations of the selected European and global standards of care, including EoLC. The COVID-19 pandemic has clearly demonstrated, also in Europe, how difficult it is to meet social, medical, and legal standards of care for terminal patients while limiting the possibility of virus transmission. Patients and their relatives suffer great mental discomfort caused by violations of certain care standards resulting from an elevated sanitary regime in medical facilities. Those regarded as violations of patients' rights and human rights in broader terms. The authors recommend standardizing and popularising the following three parallel solutions to facilitate funding: 1) Preparing and implementing technical infrastructure to make it possible for patients to meet in person with their family and relatives while preventing physical contact; 2) Extending the use of video chat technologies in hospitals and hospices; and, 3) Implementing educational activities addressed to patients, their families, and medical staff. These standards positively influence patients' quality of life and ... make it possible to meet the ethical and legal requirements of medical care. **Full text (click on pdf icon):** <https://bit.ly/37HVNdp>

From powerlessness to recognition the meaning of palliative care clinicians' experience of suffering

INTERNATIONAL JOURNAL OF QUALITATIVE STUDIES ON HEALTH & WELL-BEING | Online – 29 November 2020 – Palliative care (PC) clinicians must work alongside people who are at the end of their lives. These patients face death and suffering, which may also cause significant suffering for the PC clinicians themselves. This study's phenomenological and existential analyses of the stories related by suffering clinicians working in PC revealed that both powerlessness and non-recognition were at the core of these experiences. Such suffering was notably manifested through instances in which it was impossible to relieve patient suffering, to open up about experiences of one's own suffering, and to recognize oneself as a suffering person. Experiences of suffering and helplessness in this regard can also be understood within the larger institutional and cultural contexts, in which death is taboo and marginalized. However, enhanced perspectives can be obtained regarding the need for PC clinician support by understanding their suffering and recognizing how workplace deficits may cause distress. As such, institutional spaces should be provided to facilitate and promote mutual recognition and gratitude, which can thus circulate in a way that nourishes and heals the clinician in the context of their brave daily confrontations with the finite character of life and the suffering expressed by others. **Full text:** <https://bit.ly/33u1YAc>

N.B. Selected articles on burn-out, compassion fatigue, and the well-being and resilience practices in the hospice and PC workforce noted in Media Watch 9 November 2020 (#691, p.6).

Dying alone and lonely dying: Media discourse and pandemic conditions

JOURNAL OF AGING STUDIES, 2020;55(12):Article 100878. The authors explore current concerns and practice related to older people dying alone in intensive care units, care homes, and at home through media discussions during the COVID-19 pandemic and before. It addresses the historically-situated concept of a good death and a bad death and suggests why dying alone, whether completely alone or without significant others physically present, may be considered a bad death. Contemporary dying involves conditions for which we are unprepared as a society. We seldom address our civic obligations to each other. Few people have discussed their wishes about their preferences in dying and whether and how they want to be accompanied at their death, if possible. This is an invisible constraint of modern healthcare. Because of limited discussions and preparation, these deaths may lead to disenfranchised grief for the mourners. Cultural and societal responses to lonely dying are important in easing the emotional burden of dying alone, helping individuals prepare for this possibility and better integrating death with the life course. Recommendations include inclusion of accompaniment/non-accompaniment at death as part of advance care planning and mitigation if this condition occurs. It is essential for individuals to find their own still point of acceptance within competing societal narratives of privileging the self in dying alone and the value of social connection. **Full text:** <https://bit.ly/3mHIUWW>

A scoping review of end-of-life communication in international palliative care guidelines for acute care settings

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 1 December 2020 – End-of-life (EoL) communication in acute care settings can be challenging and many patients and families report dissatisfaction with those conversations. Thirteen guidelines from nine different countries were identified. Thematic analysis produced eight themes: 1) The purpose and process of EoL communications; 2) Cognitive understanding and language in EoL communication; 3) Legal aspects of EoL communication; 4) Conflicts and barriers related to EoL care; 5) EoL communication related to medical record documentation; 6) Healthcare professionals' responsibilities and collaboration; 7) Education and training; and, 8) Policies, guidelines, and tools for EoL communication. Palliative and EoL guidelines applicable to acute care settings outline the purpose of EoL communication and address how, when and by whom such conversations are best initiated and facilitated. How guidelines are developed and what aspects of communications are included and emphasised may differ across countries related to role differences of physicians and nurses and national laws and regulations. **Abstract (w. list of references):** <https://bit.ly/3lpJHu8>

Related:

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 26 November 2020 – **'Family caregivers' perceived communication self-efficacy with physicians.** Family-centered healthcare requires successful communication between patient, family caregivers (FCGs), and healthcare providers. Among all providers, physicians are most likely to interact with caregivers. This study examined perceived communication self-efficacy with physicians among four types of caregivers: Manager, Partner, Carrier, and Lone. An online cross-sectional survey of 220 FCGs currently caring for an adult family member revealed significant differences in communication self-efficacy among family caregiver communication types... **Abstract (w. list of references):** <https://bit.ly/2VeLoQn>

Compassion outside of the box

The role of allied healthcare professionals in providing a companion service for patients at the end of life during the COVID-19 pandemic

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 November 2020 – In response to the COVID-19 pandemic, National Health Service (NHS) England prohibited people visiting acute hospital trusts. An End-of-Life Companion scheme was introduced to support the delivery of care for seriously unwell and dying patients during this time. This study aimed to capture the companions' experience and activities, including qualitative feedback, as well as outline recommendations for this role in future services and training. The companions service comprised of allied healthcare professionals (AHPs) working for the Trust who volunteered for the role following a reduction in their normal workload due to COVID-19. They worked in shifts covering a 12-hour period every day of the week with patients identified by the palliative care team. This study highlights an interesting approach to changing job roles for healthcare professionals during the COVID-19 pandemic as well as recognising the importance of AHPs in the multi-disciplinary approach to palliative and end-of-life care. **Abstract (w. list of references):** <https://bit.ly/36mz7jq>

Noted in Media Watch 27 July 2020 (#676, p.8):

- *HEALTH EXPECTATIONS* | Online – 19 July 2020 – **“As soon as you've been there, it makes it personal”: The experience of healthcare staff shadowing patients at the end of life.** The authors uncover the nature of the most challenging aspects of the work of shadowing for healthcare staff, which proved to be emotional, rather than practical, professional, logistical or ethical. The emotions felt by shadowers in response to their experience of being with patients in this way were complex, and at the heart was the way that new perspectives afforded were “unusual.” Participants in this study found they were accompanying patients, seeing the familiar from unfamiliar vantage points, which created new emotional responses to the patients and what they were experiencing. **Full text:** <https://bit.ly/2ZLJ5r7>

What exactly is “complicated” grief? A scoping research literature review to understand its risk factors and prevalence

OMEGA – JOURNAL OF DEATH & DYING | Online – 1 December 2020 – Most people will experience bereavement grief, but some suffer from persistent or prolonged (PoP) grief, grief that used to be identified as “complicated” before recent *Diagnostic & Statistical Manual of Medical Disorders-5* and *International Classification of Diseases-11* definitional developments. A scoping literature review was undertaken to identify and consolidate contemporary evidence from research articles published in 2018 or 2019 in paper-based and open access peer-review journals on: 1) The incidence or prevalence of PoP grief; and, 2) Who develops it or is diagnosed as suffering from it, and correspondingly what causative factors or predictors are associated with PoP grief. All of the 11 identified research articles reported an incidence or prevalence rate, with these varying greatly, but with a much higher rate now that a 6-month post-death measurement timeframe is used. The predictors or factors among people who were identified as having PoP grief also varied considerably, although sudden and unexpected deaths were often implicated. **Abstract (w. list of references):** <https://bit.ly/2VoXKW3>

The prevalence of childhood bereavement in Scotland and its relationship with disadvantage: The significance of a public health approach to death, dying and bereavement

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 2 December 2020 – There is an absence of research on the prevalence of bereavement during early childhood and the relationship between childhood bereavement and socio-economic status and this poses a challenge in both understanding and supporting children’s bereavement experiences. Using longitudinal data from the Growing Up in Scotland study, which tracks the lives of three nationally representative cohorts of children, the authors aim to address these gaps in research. The study found that 50.8% of all children are bereaved of a parent, sibling, grandparent or other close family member by age 8 and this rises to 62% by age 10. The most common death experienced was that of a grandparent or other close relative. The study also found that children born into the lowest income households are at greater risk of being bereaved of a parent or sibling than those born into the highest income households. Given the prevalence of childhood bereavement and its relationship with disadvantage, the authors argue that there is an important need to understand bereavement as a universal issue that is affected by the social conditions in which a child becomes bereaved, as well as an individual experience potentially requiring specialist support. The authors seek to position childhood bereavement more firmly within the public health approach to palliative and bereavement care discourse and contends that doing so provides a unique and comprehensive opportunity to better understand and holistically respond to the experience of bereavement during childhood. **Full text:** <https://bit.ly/37nCs0K>



N.B. See ‘The Crossroads of Grief: Understanding Grief & Diversity,’ Children & Youth Grief Network, Ontario, Canada, 2018. **Download/view literature review at:** <http://bit.ly/2OB4Y6C>

Implementing person-centred outcome measures in palliative care: An exploratory qualitative study using Normalisation Process Theory to understand processes and context

PALLIATIVE MEDICINE | Online – 29 November 2020 – Despite evidence demonstrating the utility of using Person-Centred Outcome Measures within palliative care (PC) settings, implementing them into routine practice is challenging. Most research has described barriers to, without explaining the causal mechanisms underpinning, implementation. Implementation theories explain how, why, and in which contexts specific relationships between barriers/enablers might improve implementation effectiveness but have rarely been used in PC outcomes research. The aim of this study was to understand and explain the processes that underpin successful implementation of outcome measures within a PC context. Factors influencing implementation resided at individual and organisational levels. For individuals, it was important that staff were confident in their understanding of which measures to use, when, how, and why, and felt included in the

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implementation process. At an organisational level, important factors to implementation included: ensuring up-to-date and regular training for staff, that effective electronic systems were in place to input, view, and extract outcome measures, everyday practice was built around their use, and that staff using measures were provided with timely feedback. Addressing these factors is key to driving the implementation and sustained use of outcome measures by facilitating behaviour change in staff and creating environments in which their effective and safe use is possible. The authors provide key questions that are essential to consider in dealing with these issues. **Full text:** <https://bit.ly/3lobpaq>

Serious illness conversation-evaluation exercise: A novel assessment tool for residents leading serious illness conversations

PALLIATIVE MEDICINE REPORTS, 2020;1(1):280-290. To the authors' knowledge, this study is the first to demonstrate validity evidence of using the SIC-evaluation exercise (SIC-Ex) for resident trainees interviewing outpatient cancer patients. It brings together the Serious Illness Conversation framework in the context of competency-based medical education (CBME) evaluation and to validate domain-specific, total domain, and global scores and narrative comments. CBME is "an approach to preparing physicians for practice that is fundamentally oriented to graduate outcome abilities and organized around competencies derived from an analysis of societal and patient needs." The Medical Oncology Subspecialty at the Royal College of Physicians & Surgeons of Canada defines "discussing serious news" and "transitioning away from active anti-cancer therapy" as professional activities that can be entrusted to trainees once their component core competencies have been achieved. The SIC-Ex was constructed around these competencies. As SIC-Ex is a performance-based, formative evaluation process composed of multiple key milestones and integrating multiple domains of competencies, the outcomes (competencies) are not isolated elements of knowledge or a skill, but rather are integrated and observed/measured to ensure their acquisition. This study demonstrates that it is feasible to assess a trainee's competence by incorporating elements of a pre-existing evidence-based communication tool. **Full text:** <https://bit.ly/33tXVnu>

Publishing Matters

Predatory nursing journals: A case study of author prevalence and characteristics

NURSING ETHICS | Online – 3 December 2020 – Predatory publishing poses a fundamental threat to the development of nursing knowledge. Previous research has suggested that authors of papers published in predatory journals are mainly inexperienced researchers from low- and middle-income countries. Less attention has been paid to contributors from high-income countries. Almost two-thirds of Swedish authors publishing in predatory nursing journals hold senior academic positions. A small group of higher education institutions account for a majority of academic affiliations. Findings suggest that higher education institutions and experienced nursing researchers from Sweden make substantial contributions to predatory nursing journals, but that predatory publication habits might be concentrated in a limited number of academics and research milieus. A year-to-year comparison indicates that the prevalence of publishing in predatory journals might be diminishing. Swedish nurse researchers help legitimize predatory journals, thus jeopardizing the trustworthiness of academic nursing knowledge. Substandard papers in predatory journals may pass as legitimate and be used to further academic careers. Experienced researchers are misleading junior colleagues, as joint publications might become embarrassments and liabilities. While the academic nursing community needs to address the problem of predatory publishing, there is some hope that educational efforts might have an effect on combating predatory publishing in nursing. **Full text:** <https://bit.ly/2JQUVdR>



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If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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