

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 current palliative care integration model relies on oncologists to recognize unmet needs and then refer patients and thus is doomed to fail amid incomplete understanding of palliative care and its benefits.

'Why are we failing to do what works? Musings on outpatient palliative care integration in cancer care' (p.8), in *JCO Oncology Practice*.

Canada

Changes to assisted-dying rules put psychiatrists in an impossible position

THE GLOBE & MAIL | Online – 28 December 2021 – Earlier this year, the federal government expanded physician-assisted death laws to apply to people with chronic medical problems even if they have years or decades to live. Unbeknownst to many, it also set up a process that will almost certainly result in death becoming available, in the near future, as an intervention for chronic mental illnesses. This is destined to create a massive legal quagmire, which, unfortunately, hasn't got the attention it deserves. Importantly, these are not issues that the government's forthcoming recommendations, set to be released by this coming March, will be able to resolve. The issue is that, despite much discussion and rhetoric, there is essentially no science behind the practice of physician assisted death for mental illness. There has never been a study examining how often intolerable suffering exists after comprehensive psychiatric treatment, let alone whether

psychiatrists have any ability to accurately predict when that might be the case (as would be required by Canadian law). We don't even have a proper scientific definition for the concept of "enduring and intolerable suffering," which is at the crux of the legislation. If our government endorses death as a means of coping with mental illness, this could have a tragic impact on many areas of mental-healthcare, including suicide prevention. In a vacuum of scientific evidence, we are in extreme danger of breaching one of the foundational ethical dictums of medicine: "First, do no harm." <https://tgam.ca/3ECbroQ>

Specialist Publications

'Palliative in a pandemic' (p.9), in *Canadian Medical Association Journal*.



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U.S.A.

Black-owned hospice seeks to bring greater ease in dying to Black families

TENNESSEE | North Country Public Radio (Nashville) – 28 December 2021 – Heart & Soul Hospice is owned and operated by people who share the same cultural background as the patients they're trying to serve. In their application to obtain a certificate of need in Tennessee, the hospice owners made it clear that they are Black and that they intend to serve everyone but will focus on African Americans, who are currently underserved. Tennessee data show that in Nashville, just 19% of the hospice patients are Black though they make up 27% of the population. Though the area already had numerous hospice agencies, regulators granted the permission, based primarily on the value of educating an underserved group. National data shows Black Medicare patients and their families are not making the move to comfort care as often as white patients are. Roughly 41% of Black Medicare beneficiaries

who died in 2019 were enrolled in hospice, compared with white patients for whom the figure is 54%, according to data compiled annually by the National Hospice & Palliative Care Organization.¹ Hospice research hasn't come up with clear reasons why there's a gap between white and Black families' use of the benefit. Some speculate it's related to spiritual beliefs and widespread mistrust in the medical system due to decades of discrimination. <https://n.pr/3sLpFS2>

Specialist Publications

'Disparities and racism experienced among older African Americans nearing end of life' (p.10), in *Current Geriatrics Reports*.

1. 'National Hospice & Palliative Care Organization's Facts and Figures,' October, 2021. [Noted in Media Watch 1 November 2021 (#741, p.3)] <https://bit.ly/3jNMwHc>

N.B. Heart & Soul Hospice website: <https://bit.ly/3n1Vti7>

Private equity is gobbling up hospice chains and getting involved in the business of dying

HUFFPOST | Online – 21 December 2021 – For the past several years, hospice has grown to resemble the rest of the healthcare industry in one crucial aspect: Private equity is gobbling up an alarming share of the market. Today, private equity firms are acquiring American hospices at an astonishing rate. From 2012 to 2019, the number of hospices owned by private equity companies tripled. The pace of acquisitions seems to have only gotten faster during the COVID-19 pandemic. Industry brokers who have never before put together a deal involving private equity say they now field calls from private equity buyers multiple times a week. Tempted by a wave of retiring baby boomers, the-sky's-the-limit Medicare payments, the mom-and-pop nature of the industry and a lack of regulation that is pretty startling even by U.S. standards, private equity now accounts for three out of every five new hospice acquisitions. <https://bit.ly/3stb4L4>

N.B. See 'Private equity and healthcare delivery,' *Journal of the American Medical Association*, 2021;326(24): 2533-2534. **Access article at:** <https://bit.ly/3evYAtO>

Noted in Media Watch 4 October 2021 (#737, p.8)

- *JAMA HEALTH FORUM*, 2021;2(9):e213745. '**Hospice acquisitions by profit-driven private equity firms.**' Profit is a key, driving focus of many businesses. Although private equity investment in healthcare could lead to improvement by injecting needed capital, a pressing concern is that many private equity firms often operate on the model of buying and quickly selling for a substantial profit within three years. A recent commentary on private equity used the metaphor of an experiment that observed what happened to an ecosystem when a new predator was introduced: contrary to the hypothesis that this event would lead to an improved ecosystem, the opposite occurred. We are now witnessing a natural experiment in the hospice market. **Full text:** <https://bit.ly/3utOHUA>

Cont.

Noted in Media Watch 26 July 2021 (#727, p.7):

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 18 July 2021 – ‘**Differences between for-profit and non-profit hospice agencies in the U.S. Medicare population.**’ Most Medicare beneficiaries are enrolled in for-profit vs non-profit hospice agencies, which cost Medicare 34% more per beneficiary. Higher total costs of care directly relate to longer lengths of stay in for-profit agencies, even when accounting for lower reimbursement rates for days 61 and greater. This difference could be explained by for-profit agencies enrolling more patients with dementia, who live longer in hospice than cancer patients, who have greater acuity yet shorter survival in hospice. Cost of care was higher in for-profit agencies even though they provided higher proportion of routine home care days. **Full text:** <https://bit.ly/3wKspxu>

N.B. Search back issues of Media Watch for additional articles on “for-profit” and “non-profit” hospices in the U.S. at : <http://bit.ly/2ThijkC>

International

GPs offered teenage patients with autism and Down’s syndrome ‘do not resuscitate’ orders during routine appointments at the height of the Covid pandemic – leaving some confused and upset, parents reveal

U.K. (England) | *The Daily Mail* (London) – 26 December 2021 – Teenagers with autism and Down’s syndrome were offered do not resuscitate orders (DNR) during routine appointments with their GP during the pandemic, it has emerged. Many parents believe their child has been “discriminated against” and say they were only asked about the order because of their learning disability. The DNR orders were reportedly offered following “concerns about the pressure on the National Health Service (NHS)” – but it has left families confused and “upset.” NHS England wrote to medics last year as the pandemic struck reminding them of guidance that learning disability should never be a reason for issuing a DNR. Shocked parents are now worried their child could have agreed to the order because they may have not “understood the question.” The DNR orders – also known as ‘Do Not Attempt Cardiopulmonary Resuscitation’ – are given to seriously ill patients and prevent doctors from performing

CPR. Guidance states they should only be put in place on an individual case-by-case basis after discussion with a patient or their family about end-of-life plans. <https://bit.ly/3sD67PC>

Night nurses in high demand as patients choose to die at home

IRELAND | *Extra.ie* (Dublin) – 28 December 2021 – Demand for night nurses has risen throughout the pandemic as more people opt to die at home with restrictions in hospitals separating the dying from their loved ones. The service, offered by the Irish Cancer Society, provides end-of-life care for cancer patients in their own home between 11 p.m. and 7 a.m. Between January and September 2021, the Irish Cancer Society night nurses provided 5,666 nights of care to allow dying patients to spend their final days surrounded by their loved ones – and it noted an increase in demand since the introduction of visiting restrictions in hospitals. <https://bit.ly/3JlwNud>

Noted in Media Watch 22 March 2021 (#709):

- U.K. | *The Independent* (London) – 18 March 2021 – ‘**Hundreds of patients including care home residents subjected to unlawful “do not resuscitate” orders, Care Quality Commission confirms.**’ Hundreds of elderly patients have been subjected to unlawful do not resuscitate decisions that included blanket orders on care home residents... In a review of the use of the controversial notices during the pandemic, the Care Quality Commission said it had uncovered evidence of patents not being involved in discussions and in some cases even being denied treatment.¹ Care home providers told the watchdog there were a total of 508 do not attempt cardiopulmonary resuscitation decisions that had been put in place after 17 March last year without any discussion with the patient or their family. <http://bit.ly/3ltbOu2>

1. ‘Protect, respect, connect – decisions about living and dying well during COVID-19,’ Care Quality Commission, March 2021. <http://bit.ly/3eMn6ly>

Cont.

Noted in Media Watch 3 August 2020 (#677, p.4):

- U.K. (England) | *The Daily Mail* (London) – 28 July 2020 – **‘More than half of adult Coronavirus patients at a leading hospital were given do not resuscitate orders or barred from treatment in intensive care, study reveals.’** More than half of all adult patients treated for Corona-virus at a leading hospital were given do not resuscitate orders (DNR) or barred from treatment in intensive care...¹ Less than one in five patients ... was admitted to the intensive care unit. 61% of COVID-19 patients had treatment limitations placed on them on admission to King’s College Hospital... This meant they were denied access to potentially life-saving care. The study raises new fears about care rationing for elderly and vulnerable patients amid concerns they were rushed into agreeing to a DNR order. <http://dailym.ai/307J2pN>

1. ‘Hospital mortality and resource implications of hospitalisation with COVID-19 in London: A prospective cohort study,’ *medRxiv* posted 17 July 2020. **Full text:** <https://bit.ly/3gc9152>

National Health Service pressures having “devastating” impact on dying patients

U.K. (England) | *The Independent* (London) – 24 December 2021 – Patients are dying in hospital without their families because of pressure on National Health Service (NHS) services... A major care provider has warned that it has seen a “huge shift” in the number of patients referred too late to its services. The warning comes as NHS England begins a new £32 million contract with hospices to help hospitals discharge as many patients as possible this winter. NHS chief executive Amanda Pritchard said the health service was preparing for an Omicron-driven COVID wave that could be as disruptive as, or even worse than, last winter’s crisis. Hospices are already dealing with a “huge volume of death and patients needing support,” according to the head of policy at Hospice UK, Dominic Carter. He told *The Independent* that hospices had seen a huge shift in the number of patients referred to their services too late, when they are in a “very serious” state of health. He added: “We don’t really know what kind of support is actually out there for those people, while hospitals have difficulties and deal with challenges around backlogs and Covid. There are lots of people that have been in the community, where hospices are trying to reach them, but aren’t

always able to identify who needs that care and support. “They’re really important, those five or six final days, for the individual and their families. Yet this is spent in crisis rather than being helped as much as possible in a comfortable environment by the hospice ... [instead] an ambulance is called, and they’re having to be cast into hospital.” <https://bit.ly/33Yltmz>

Specialist Publications

‘Progress update: Palliative care development between 2017 and 2020 in five African countries’ (p.14), in *Journal of Pain & Symptom Management*.

‘Cross-country comparison of expert assessments of the quality of death and dying 2021’ (p.8), in *Journal of Pain & Symptom Management*.

‘Teaching about death and dying: A national mixed-methods survey of palliative care education provision in Swedish undergraduate nursing programmes’ (p.15), in *Scandinavian Journal of Caring Sciences*.

Related:

- IRELAND | *The Irish Times* (Dublin) – 23 December 2021 – **‘Palliative care services “curtailed” for new patients in north east.’** Palliative care (PC) services have been “curtailed” for new patients across four counties in the north-east of the country, to deal with a large backlog of referrals built up due to COVID-19 staff absences. The Health Service Executive (HSE) has said the decision will affect services in Louth, Meath, Cavan and Monaghan. Health officials wrote to general practitioners (GPs) in the affected counties in recent days, stating the HSE would be “unable to respond” to any new patients referred for specialist PC. The correspondence stated the decision followed an “unprecedented” increase in referrals from GPs, alongside a “surge” in referrals from hospitals as well. <https://bit.ly/3elTmAK>

Psychiatrists group raises concerns with assisted dying bill

IRELAND | *The Journal* (Dublin) – 20 December 2021 – A group representing 1,000 psychiatrists in Ireland has said that it is against physician assisted dying, ahead of a proposed new law to be debated by a special Oireachtas committee next year. The College of Psychiatrists of Ireland has said today that physician-assisted dying “is not compatible with good medical care and that its introduction in Ireland could place vulnerable patients at risk.” The College is the professional and training body that represents 1,000 professional psychiatrists, both specialists and trainees, across the country. It has published a position paper on assisted dying,¹ stating assisted dying is “contrary to the efforts of psychiatrists, other mental health staff and the public to prevent deaths by suicide.” It also believes that it is likely “to place vulnerable people at risk – many requests for assisted dying stem from issues such as fear of being a burden or fear of death rather than from intractable pain.” The group is concerned that it will be introduced for people with terminal illnesses, but that it will then be “applied more broadly to other groups.” <https://bit.ly/3GVQI0U>

1. ‘Physician Assisted Suicide and Euthanasia,’ College of Psychiatrists of Ireland, September 2021: <https://bit.ly/30HGfXm>

Extract from College of Psychiatrists of Ireland position paper: ‘Psychological suffering and palliative care’

Psychiatric complications at the end of life (EoL) are treatable, but often go unrecognized and untreated. There are many reasons for this: difficulty in diagnosing and treating psychiatric disorders (e.g., anxiety, delirium, depression) in the setting of significant physical illness, owing to the overlap in the symptoms caused by the psychiatric disorder and the co-morbid physical problems; beliefs held by many patients, family members, physicians and hospice and palliative care providers whereby psychiatric symptoms, especially depression, are viewed as normal parts of the dying process; and, the fact that many patients and physicians do not understand that patients who suffer from mental disorders at the EoL can respond to treatment. This therapeutic nihilism inhibits the search for treatable mental disorders at the EoL.

[Specialist Publications](#)

‘Dying with assistance: The call for an inquiry, the power of a declaration, the role of evidence’ (p.15), in *Medical Law Review*.

[Specialist Publications](#)

Acknowledging bereavement, strengthening communities: Introducing an online compassionate community initiative for the recognition of pandemic grief

AMERICAN JOURNAL OF COMMUNITY PSYCHOLOGY | Online – 22 December 2021 – Despite public health measures and collective efforts, millions of individuals have unfortunately died from COVID-19 complications worldwide, leaving several million family members at risk of developing bereavement complications. In the Canadian province of Quebec, where substantial deaths were associated with COVID-19, the authors established an online support community for bereaved caregivers who lost a loved one during the pandemic. In this article, they explain how they created a community that recognized pandemic grief and advocated for its wider acknowledgment. They discuss “compassionate communities,” the theoretical underpinning of their initiative, as a means to foster solidarity, normalize finitude, create and maintain a safe social space through group sharing, and challenging capitalist principles. The authors then describe the eight areas of activities inspired by the Charter of Pallium Canada: education and training, hospices and nursing homes, media and social media, commemoration, celebrations, artistic practices and storytelling, marginalized populations, and review and evaluate. The authors propose that online communities constitute a powerful space for community members to gather and advocate for greater awareness of the inequities found in end-of-life care and bereavement services, to denounce abusive situations experienced by many individuals who died from COVID-19 complications, and to fight against the lack of recognition experienced by numerous caregivers. **Full text:** <https://bit.ly/3yUbv27>

Cont.

Related:

- *FRONTIERS IN PSYCHOLOGY* | Online – 2 December 2021 – ‘**Stages of grief portrayed on the Internet: A systematic analysis and critical appraisal.**’ The authors analysis reveals that the presentation of Kübler-Ross’s five stages model on websites raises a number of critical issues and implications, ones that need further consideration and which stand apart from her original contribution. Kübler-Ross’s ... ‘On Death and Dying’ provided unprecedented (albeit anecdotal) insight into the process of adaptation among terminally ill people. The historical importance of her five stages model in bringing awareness to the experience of the dying cannot be denied. However, this historical impact does not mean that the model can be used as a contemporary standard for the grieving process. **Full text:** <https://bit.ly/3moKyyu>

N.B. Search back issues of Media Watch for additional articles on “Kübler-Ross” at: <http://bit.ly/2ThijkC>

Assessing quality in advance care planning documentation: A survey of current methods

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 December 2021 –High-quality advance care planning (ACP) documentation facilitates the communication of patients’ wishes as they progress in their disease course and travel between healthcare settings. No consensus exists regarding evaluation of documentation quality, and diverse strategies for assessing quality have been adopted in clinical ACP studies. The authors identified 11 studies for inclusion in their review. Across study methodologies, the following 8 quality domains were identified: 1) Discussion frequency; 2) Documentation accessibility; 3) Discussion timing; 4) Healthcare proxy; 5) Health goals or values; 6) Scope of treatment/code status; 7) Prognosis/illness understanding; and, 8) End-of-life care planning. This review provides an adaptable framework centered around quality domains. **Abstract (w. references):** <https://bit.ly/32ExRIQ>

Facilitators and barriers to the delivery of palliative care to children with life-limiting and life-threatening conditions: A qualitative study of the experiences and perceptions of healthcare professionals

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 15 December 2021 – Healthcare professionals ... working in children’s palliative care (PC) services in four regions of England (West Midlands, South West, Yorkshire and Humber, and London) participated in focus groups. Three overarching themes emerged which influenced whether and when children were referred to and started to receive PC: 1) The unspoken background of clinical uncertainty which often delayed PC; 2) The cultural “collusion of immortality,” where conversations about the possibility of dying can be avoided or deferred; and, 3) The role of paediatric PC teams in “illuminating the blind spot” of PC as well as providing hands-on care. PC is a holistic approach to care that focuses on quality of life for people living with life-limiting and life-threatening conditions that can be delivered alongside active treatment. There is a need to prioritise and integrate this into healthcare services for children more effectively if improvements in care are to be realised. While more specialist paediatric PC services are needed, the unspoken background of clinical uncertainty needs to be addressed together with the collusion of immortality within healthcare culture and organisations. **Abstract:** <https://bit.ly/3p9z2J1>

Parents’ anticipated discussions about death with young children

OMEGA – JOURNAL OF DEATH & DYING | Online – 18 December 2021 – This mixed-methods investigation explored how parents of young children described the way they would discuss death when it comes up in conversations. Responses were coded inductively, resulting in four themes: 1) Explanations that death is inevitable; 2) Explanations that death is in the distance; 3) The use of religion to frame discussions of death; and, 4) Discussing afterlife connections to deceased family members. Logistic regression analyses were used to evaluate whether parents’ conformity or conversation orientations were associated with the frequency with which parents discussed death with their child and the content of parent vignette responses. Quantitative analysis revealed parents’ conversation orientations were associated with the frequency with which they discussed death with their child and conformity orientations were associated with parents’ use of religion and discussing afterlife connections to deceased family members in their responses. **Abstract (w. references):** <https://bit.ly/32dRPTU>

Cont.

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 December 2021 – ‘**Pediatric end-of-life care in rural America: A systematic review.**’ Three studies identified and evaluated the facilitators of end-of-life care (EoLC) for rural children. The articles identified technology and additional training as facilitators. Four studies reported on the needs of rural children for EoLC with serious illness. The authors of this article found major barriers and unmet needs in the delivery of rural pediatric EoLC. A few facilitators in delivery of this type of care were explored. Overall research in this area was sparse. Future studies should focus on understanding the complexities associated with delivery of pediatric EoLC in rural areas. **Abstract (w. references):** <https://bit.ly/3Hhpl1q>
- *BMJ OPEN QUALITY* | Online – 20 December 2021 – ‘**Chameleon project: A children’s end-of-life care quality improvement project.**’ The project provided a team of clinicians with expertise in children’s end-of-life (EoL) care who worked together to embed a system of earlier identification and personalized care planning across a region. Having paediatricians with expertise in pediatric palliative care (PC) in each district general hospital, working together with the specialist pediatric PC team in the tertiary children’s hospital, can support coordination and quality improvement of services for children with palliative and EoL care needs across a regional network with improved care and choice for children and families. **Full text:** <https://bit.ly/3moeIC0>
- *PALLIATIVE MEDICINE* | Online – 30 December 2021 – ‘**Communication strategies and persuasion as core components of shared decision-making for children with life-limiting conditions: A multiple case study.**’ Professionals presented options they believed were in the child’s best interests, emphasising their preference. Options were often presented in advance of being necessary to prevent harm, therefore professionals permitted delay to treatment. Persuasion was utilised over time when professionals felt the treatment was becoming more urgent and when families felt it would not promote the child’s psychosocial wellbeing. Communication strategies in shared decision-making are underpinned by moral work. **Abstract (w. references):** <https://bit.ly/3HqCeGn>
- *PALLIATIVE MEDICINE* | Online – 20 December 2021 – ‘**Care practices of specialized outpatient pediatric palliative care teams in collaboration with parents: Results of participatory observations.**’ Pediatric palliative care (PC) encompasses not only medical treatment, but also collaboration with and care for parents. Building a trusting relationship with parents demands time, communication skills, and psychosocial competence. These special requirements of PC for children and their families and the high communication share should be taken into account when establishing inpatient and outpatient PC structures, preparing guidelines, training staff and deciding upon appropriate remuneration. **Full text:** <https://bit.ly/3skvtBO>
- *PEDIATRIC BLOOD & CANCER* | Online – 26 December 2021 – ‘**“Some things are even worse than telling a child he is going to die”:** Pediatric oncology healthcare professionals perspectives on communicating with children about cancer and end of life.’ The rising accessibility of online information calls for urgent training of healthcare professionals (HCPs) in communication so that children will not turn to unmediated and potentially misleading information online in the absence of HCP communication. Evidence-based effective communication training modules and emotional support should be offered to HCPs. Knowledge about children’s development, age-appropriate communication, and cultural sensitivity should be included in this training. **Abstract:** <https://bit.ly/3eBBY4B>
- *PEDIATRIC RESEARCH* | Online – 18 December 2021 – ‘**Choiceless options: When hospital-based services represent the only palliative care offering.**’ Hospital-based care models may be perceived as the only viable choice due to geographic gaps in service coverage. Gaps exist not only in access to these key services, but also in service quality without national pediatric service standards. While families from rural regions may express a goal to be home with their child ... the current setting of services may limit the feasibility of home-based care. Several potential pediatric systems changes have the capacity to create and sustain a care model that allows a child with complex, chronic, or life-limiting diagnoses to experience a home other than the hospital. **Abstract (w. references):** <https://go.nature.com/3EdV5T9>



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.19.

Concerns and potential improvements in end-of-life care from the perspectives of older patients and informal caregivers: A scoping review

BMC GERIATRICS | Online – 20 December 2021 – This scoping review identified five themes that reflect older patients and informal caregiver perceptions of quality care at end of life (EoL): 1) Effective communication between clinicians and patients/caregivers; 2) Healthcare that values patient preferences and shared decision-making; 3) Models of care that support quality of life and death with dignity; 4) Healthcare services that meet patient expectations; and, 5) Support for informal caregivers in dealing with EoL challenges. Many of the issues highlighted ... are not new and have persisted over two decades, highlighting the need to embrace a multifaceted, multidisciplinary approach that addresses the many levels of the EoL experience, and ensuring that promising initiatives are translated, evaluated and scaled up. These findings are relevant to clinicians, managers and policymakers and highlight a number of solutions that can be implemented at every level to improve the quality of care at EoL. However, phase 3 trials are yet to demonstrate sustainable effectiveness of some of the proposed solutions at larger scale; and there is an urgent need for comprehensive evaluation of care across the healthcare system and targeted redesign of existing EoL care pathways to ensure care aligns with what patients and informal carers consider high-quality patient-centred care at the EoL. **Full text:** <https://bit.ly/3H61TEr>

Related:

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 27 December 2021 – ‘**A systematized approach to advancing the quality of community-based palliative care.**’ Despite growing recognition of the importance of community-based palliative care (PC), optimizing the use of services continues to be a challenge. As services have become increasingly available [in the U.S.], engagement of patients and their caregivers has emerged as a major obstacle. The Palliative Activation System™ (PAS) is a comprehensive, quality improvement methodology designed to promote enhanced engagement of seriously ill adults and their caregivers in optimizing the use of community-based PC services and accelerate clinicians’ progress in meeting patients’ and caregivers’ care goals. **Full text:** <https://bit.ly/3eyl38x>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 21 December 2021 – ‘**Cross-country comparison of expert assessments of the quality of death and dying 2021.**’ This study provides an application for how preference-weighted assessment scores can be used to quantify end-of-life (EoL) care delivery across countries. The results highlight the great disparities in the quality of EoL care across countries and especially between the highest income countries and others. The finding that, based on assessment scores provided by country experts, nearly half of countries received a grade of D or F in the quality of death and dying should serve as a stark reminder of the lack of attention to EoL care and be a call to action to improve performance. **Full text:** <https://bit.ly/3yMBVCU>

Why are we failing to do what works? Musings on outpatient palliative care integration in cancer care

JCO ONCOLOGY PRACTICE | Online – 22 December 2021 – In their recent study, Yeh *et al* add to the mounting evidence showing a myriad of benefits conferred by outpatient integrated palliative care (PC) in oncology.¹ However, despite this clear evidence, we have not achieved widespread PC implementation outside of trials. First, we must be clear in our terminology. The term PC is often misused and misunderstood as a euphemism for end-of-life care or hospice. Specialty PC is also different from the primary PC usually provided by the oncology team (e.g., basic symptom management and what is often called supportive care). In using the term PC here, we refer to sophisticated subspecialty care that aims to prevent and relieve suffering by assessment and treatment of physical, spiritual, and psychosocial problems. It is thereby appropriate at any stage of illness and can be provided even alongside curative therapies. The evidence base supporting outpatient PC integration in oncology is robust... **Full text:** <https://bit.ly/3egU9Tw>

1. ‘Different associations between inpatient or outpatient palliative care and end-of-life outcomes for hospitalized patients with cancer,’ *JCO Oncology Practice*, published online 16 December 2021. **Full text:** <https://bit.ly/3H1OxsC>

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 21 December 2021 – ‘**Reliable and valid survey-based measures to assess quality of care in home-based serious illness programs.**’ The authors developed and tested a Serious Illness Survey that assessed of a broad range of care experiences that both seriously ill individuals and experts deem most important for high-quality serious illness care in the home. The authors found support for the reliability and validity of the Serious Illness Survey for measuring and comparing care experiences. Results from the survey can be used to inform quality improvement efforts, monitor care quality over time, compare quality between programs, and assess the effectiveness of new initiatives that provide access to home-based serious illness care. **Full text:** <https://bit.ly/3Jg6BkE>

Palliative care provider attitudes toward existential distress and treatment with psychedelic-assisted therapies

BMC PALLIATIVE CARE | Online – 20 December 2021 – Palliative care (PC) providers describe existential distress as a common source of suffering for patients with life-threatening illness. Current treatments emphasize enhancement of sources of meaning and rely on interdisciplinary coordination. Clinicians view psychedelic-assisted therapies (PAT) as promising treatments for refractory existential distress, though concerns regarding access and exclusionary criteria currently limit their potential scope. Further research and education regarding psychedelic interventions are needed before PAT can be more widely adopted in PC settings, especially to address safety concerns and clarify a target population. Close collaboration with spiritual care and mental health providers and adaptations of PAT to existing meaning-focused approaches will facilitate integration into current practice. Educational outreach should address misconceptions regarding risks of substance use and psychological harm. Broader access to PAT research and greater diversity of study samples will improve generalizability and promote equitable treatment outcomes. **Full text:** <https://bit.ly/30Mny05>

Related:

- *CURRENT TOPICS IN BEHAVIORAL NEUROSCIENCES* | Online – 28 December 2021 – ‘**The potential of psychedelics for end-of-life and palliative care.**’ End-of-life (EoL) and palliative care (PC) has improved in recent decades, but the psychopharmacological options available to clinicians and patients in these contexts remain limited. In particular, psychological factors such as depression, existential distress, and well-being remain challenging to address with current medications. The authors review recent research on the use of psychedelics in clinical settings with a particular focus on patients with life-threatening diagnoses. They propose that psychedelics may provide clinicians with an additional psychopharmacological treatment in the context of EoL and PC. **Abstract (via PubMed):** <https://bit.ly/3mCXHEh>

N.B. Selected articles on psychedelic-assisted therapies in the treatment of existential suffering in palliative and end-of-life care noted in Media Watch 19 April 2021 (#713, pp.15-16).

Palliative in a pandemic

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2021;193(50):E1925-E1926. Palliation at home for ventilated patients from the ICU is uncommon, but is frequently requested by patients and their decision-makers when discussing end-of-life care (EoLC). When given the choice, patients who are terminally ill prefer to die at home, and families report higher satisfaction with care, support and respect for cultural and religious beliefs when withdrawal of life-sustaining therapy (WLST) occurs at home. Data on ventilated patients taken home for WLST come mostly from case reports, highlighting that this approach is possible, but is beset by logistical challenges and a lack of guidelines. These challenges are now further exacerbated by the COVID-19 pandemic. Respiratory therapists are indispensable in busy ICUs. Paramedic services cannot commit to non-urgent ambulance transfers. Public health restrictions limit travel, cap the number of people who can gather indoors and outdoors, and impose rules for masking and social distancing. Working through the pandemic has taken a toll on healthcare providers; the moral distress and distance it has created resonates deeply in our daily care. This act of kindness [described in this case report] empowered us to overcome this distance – to listen, to collaborate, to capitalize on the expertise, thoughts and opinions of our diverse group, and to build a robust multifaceted plan that focused on our patient. We were unified in our common

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goal and overcame the challenges the pandemic threw in the way. After a year of saying “no,” our morale was lifted by the ability to finally say “yes.” We were buoyed by the opportunity to honour our patient’s wish; however, the incentive was larger than that. In a time when compassionate EoLC was more challenging than ever, bringing Lucille home showed us that, although the circumstances may be different, the opportunity to bestow the empathetic care we are accustomed to providing is possible with the engagement and creative thinking of our exceptional team. **Full text:** <https://bit.ly/3EfKrLL>

Related:

- *PALLIATIVE MEDICINE* | Online – 29 December 2021 – ‘**Understanding the impact of the Covid-19 pandemic on delivery of rehabilitation in specialist palliative care services: An analysis of the CovPall-Rehab survey data.**’ This study provides evidence of the impact that COVID-19 had on rehabilitation services working in palliative care within the U.K. The pandemic forced shifts to remote provision and impacted the capacity of health professionals and patients to deliver and participate in rehabilitation. Evidence is provided on how the pandemic may act as a springboard for positive future changes through the adoption of hybrid approaches to rehabilitation that integrate remote and face-to-face provision in ways that are able to expand reach and improve equity. **Full text:** <https://bit.ly/3qBqQRi>

Disparities and racism experienced among older African Americans nearing end of life

CURRENT GERIATRICS REPORTS | Online – 14 December 2021 – There is an unacceptable difference in the way African Americans receive end-of-life (EoL) care. It is critical that systemic racism in healthcare be addressed to ensure equitable care. The first step is recognizing, acknowledging, and respecting the inequity, disrespect, and disregard African American patients have experienced. Next, systemic and individual racism must be addressed at multiple levels: policy level, institutional level; community wide, and individually. Moreover, institutions must partner with communities to build trust between African Americans and the healthcare system. Finally, and most importantly, the voices of the African American community must be heard, there needs to be more representation of African Americans in healthcare, and partnerships between institutions that provide healthcare and the community must be formed if we are to truly achieve health equity for African Americans at EoL. **Full text:** <https://bit.ly/3HfrxGM>

N.B. Search back issues of Media Watch for additional articles on “disparities” and “racism” in the U.S. healthcare system in the context of palliative and end-of-life care at: <http://bit.ly/2ThijkC>

Palliative care organization and staffing models in residential hospices: Which makes the difference?

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – Accessed 20 December 2021 – The number of patients using palliative care (PC) services, particularly residential hospices, is increasing. Policymakers are urging these services to reflect on the most effective organizational strategies for meeting patients’ complex care needs. This study shows the exact skill-mix composition and proportions of PC team able to ensure optimal control of patients’ symptoms. The added value of physicians and nurses with a qualification in PC in terms of better patient outcomes reaffirmed the importance of education in guaranteeing quality care. Hospices with 12-25 beds, and recruitment methods guaranteeing at least 12-day stay ensured the most propitious organizational environment for optimal management of clinically significant symptoms. The transferability of these results mainly depends on whether the skills of health professionals in our “ideal” model are present in other contexts. The authors’ results provide policymakers and hospice managers with specific, evidence-based information to support decision-making processes regarding hospice staffing and organization. **Abstract:** <https://bit.ly/3mlhbgq>

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Palliative Care Network

Palliative Care for Everyone, Everywhere

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

Related:

- *JOURNAL OF PALLIATIVE CARE* | Online – 23 December 2021 – ‘**A national survey of palliative care team compositions.**’ This national survey examined the team composition in palliative care (PC) programs at all 61 National Cancer Institute (NCI)-designated cancer centers in the U.S. and in a random sample of 60 of 1,252 non-NCI-designated cancer centers in 2018. Between 2009 and 2018, NCI-designated and non-NCI-designated cancer centers saw increased proportions of centers with interprofessional teams. NCI-designated cancer centers were more likely to report having an interprofessional PC team than non-NCI-designated cancer centers. Growth has been limited over the past decade, particularly at non-NCI-designated cancer centers. **Abstract (w. references):** <https://bit.ly/3svg55G>

A review and content analysis of U.S. Department of Corrections end-of-life decision making policies

INTERNATIONAL JOURNAL OF PRISONER HEALTH | Online – 27 December 2021 – With a rapidly growing population of older adults with chronic illness in U.S. prisons, the number of people who die while incarcerated is increasing. Support for patients’ medical decision-making is a cornerstone of quality care for people at the end of life (EoL). This study collected and reviewed available policies from 37 of 51 prison systems (73%). Some areas of commonality included the importance of establishing healthcare proxies and how to transfer EoL decision documents, although policies differed in terms of which patients can complete advance care planning documents, and who can serve as their surrogate decision-makers. Many prison systems have an opportunity to enhance their patient medical decision-making policies to bring them in line with community standard quality of care. In addition, this study was unable to locate policies regarding patient decision-making at the EoL in one quarter of US prison systems, suggesting there may be quality-of-care challenges around formalized approaches to documenting patient medical wishes in some of those prison systems. To the best of the authors’ knowledge, this is the first content analysis of EoL decision-making policies in U.S. prison systems. **Abstract:** <https://bit.ly/3H7DaiW>



Prison Hospice: Backgrounder
Updated 1 November 2021

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 from the Palliative Care Network website: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk, Philadelphia, PA

Related:

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 31 December 2021 – “‘**Dying with a smile, just knowing that somebody’s listened to me**’”: **End-of-life care and medical assistance in dying in Canadian prisons.**’ Sound policies and guidelines require both generalizable principles and attention to nuance. When it comes to impending death, understanding and uplifting an individual’s dying wishes is central to patient-centered care. It would be difficult to justify an end-of-life care (EoLC) policy as either practicable or ethical if it denies autonomy to a patient that is otherwise mentally fit and capable of consent, on the basis of their legal status in the prison system. Especially because prisoners have had many freedoms removed, autonomy over EoLC decisions is paramount. **Full text:** <https://bit.ly/3eFoWtl>

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- *PALLIATIVE MEDICINE* | Online – 30 December 2021 – ‘**Palliative care needs and experiences of people in prison: A systematic review and meta-synthesis.**’ Experiences of people in prison regarding palliative care (PC) related to two themes: 1) Expectations versus experiences of PC; and, 2) Prison context complicates access to and provision of PC. People in prison with PC needs want to feel safe, cared for, and acknowledged as they face an expected death. The prison environment can severely restrict access to PC, leaving people in prison feeling isolated and powerless. Numerous structural and organisational challenges complicate the provision of PC in prisons, limiting accessibility of care. **Abstract (w. references):** <https://bit.ly/3sKtXJm>

N.B. Palliative Care in Prisons Project, University of Technology Sydney, Australia: <https://bit.ly/32GrcOy>

High-quality nursing home and palliative care – one and the same

JOURNAL OF AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 23 December 2021 – Many individuals receiving post-acute and long-term care (LTC) services in nursing homes have unmet palliative and end-of-life care (EoLC) needs. Hospice has been the predominant approach to meeting these needs, although hospice services generally are available only to LTC residents with a limited prognosis who choose to forego disease-modifying or curative therapies. Two additional approaches to meeting these needs are the provision of palliative care (PC) consultation through community- or hospital-based programs and facility-based PC services. However, access to this specialized care is limited, services are not clearly defined, and the empirical evidence of these approaches’ effectiveness is inadequate. In this article, the authors review the existing evidence and challenges with each of these three approaches. They then describe a model for effective delivery of palliative and EoLC in nursing homes, one in which palliative and EoLC are seen as integral to high-quality nursing home care. To achieve this vision, the authors make four recommendations: 1) Promote internal palliative and EoLC capacity through comprehensive training and support; 2) Ensure that state and federal payment policies and regulations do not create barriers to delivering high-quality, person-centered palliative and EoLC; 3) Align nursing home quality measures to include palliative and EoLC-sensitive indicators; and, 4) Support access to and integration of external PC services. These recommendations will require changes in the organization, delivery, and reimbursement of care. All nursing homes should provide high-quality palliative and EoLC, and this article describes some key strategies to make this goal a reality. **Abstract:** <https://bit.ly/32rb2sq>

Noted in Media Watch 31 May 2021 (#719, p.5):

- *BMC GERIATRICS* | Online – 22 May 2021 – ‘**Multi-disciplinary supportive end-of-life care in long-term care: An integrative approach to improving end of life.**’ This Canadian study identified three key recommendations. The first is to establish knowledge and training expectations and resources for long-term care (LTC) staff and physicians, which focuses on a palliative approach, mentorship, communication and collaboration in LTC. The second is to build connections between all those involved in providing end-of-life care (EoL) care, including family members. The third is to create policies and provide funds needed to meet comfort care needs at EoL. Considering the identified priorities, the authors developed a 5-point strategy to providing supportive EoL care within LTC. **Full text:** <https://bit.ly/3fcD6mO>

Noted in Media Watch 4 January 2020 (#698, p.1):

- *HEALTHY DEBATE* | Online – 28 December 2020 – ‘**If not now, when? Applying a palliative approach in long-term care.**’ Earlier this month, the federal government committed to a \$1-billion investment into long-term care (LTC) homes across Canada over two years as part of its economic update. While the investment is welcome, and greatly needed, there is an omission in the list of deliverables, one we believe would greatly enhance the quality of LTC services across Canada – committing to, or deepening the commitment to, a palliative approach to care in long-term homes. The pandemic’s impact on LTC has been unprecedented and has exposed the growing trend over the last several years towards increased numbers of residents dying in LTC. <http://bit.ly/2Mj8ggj>



Would the *Journal of American Medical Directors Association* article be of interest to a colleague?

Addressing spiritual needs in palliative care: Proposal for a narrative and interfaith spiritual care intervention for chaplaincy

JOURNAL OF HEALTH CARE CHAPLAINCY | Online – 19 December 2021 – The proposed intervention provides a useful frame for chaplains practicing spiritual provision in palliative care, for several reasons. First, the systematic nature of this intervention supports the need for more outcome-oriented and evidence-based chaplaincy. Second, it supports chaplains to articulate what their contribution and value is, which is a necessity for the development of the chaplaincy profession as such. Third, the intervention connects the spiritual needs that can arise in the palliative phase with a systematic methodology for chaplains to respond to these spiritual needs and work towards the goal of strengthening patients' spiritual wellbeing. Working with such a structured intervention may support chaplains to be increasingly recognized by other care workers as equal professionals in the healthcare process. Although working with clear methodologies and with an articulated aim is still in its infancy in the field of chaplaincy, the development of evidence-based interventions for chaplains will improve spiritual care provision and will be a fruitful step for further developing the chaplaincy profession. **Full text:** <https://bit.ly/32dwH79>

N.B. Selected articles on the role of chaplaincy in palliative and end-of-life care noted in Media Watch 25 October 2021 (#740, pp.12-13).

Related:

- *INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH* | Online – 26 December 2021 – **'Spirituality in patients at the end of life: Is it necessary? A qualitative approach to the protagonists.'** Spirituality is the most unknown aspect of palliative care despite being the need that is most altered in the last moments of life. The object of this study was to identify on the one hand the spiritual needs of patients who are at the end of life (EoL) and on the other hand the way in which nursing professionals can work to provide effective accompaniment in this process. The provision of spiritual care gives meaning to the actions of nursing professionals when it comes to providing EoL care, achieving holistic care, humanizing death, and promoting a dignified end. **Full text:** <https://bit.ly/3qpUKln>

Doulas from cradle to grave: Integration into conventional medical care

JOURNAL OF LAW & MEDICINE, 2021;28(4):946-954. Doulas are becoming increasingly popular as support persons for the critical processes of birth and death. There is some evidence that their support reduces interventions such as Caesarean sections and instrumental deliveries as well as medicated pain relief. However, there are clear tensions in Australia between doulas and the professional obstetric staff such as midwives and obstetricians. Especially if they challenge proposed obstetric management on behalf of parturient women. Their role in managing the dying may also be open to malfeasance. At present Australian doulas are not regulated by the Australian Health Professionals Regulation Authority but there is a need for them to be regulated at a local and State or Territory level. **Abstract (via PubMed):** <https://bit.ly/32hC19k>

N.B. Search back issues of Media Watch for additional articles on end-of-life "doulas" at: <http://bit.ly/2ThijkC>



[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>

Neuropalliative care for the neurosurgeon: A primer

JOURNAL OF NEUROSURGERY | Online – 17 December 2021 – Many neurosurgical conditions are incurable, leading to disability or severe symptoms, poor quality of life, and distress for patients and families. Neuropalliative care (NPC) addresses the palliative care (PC) needs of individuals living with neurological conditions. Neurosurgeons play an important role within multidisciplinary NPC teams because of their understanding of the natural history of and treatment strategies for neurosurgical conditions, longitudinal patient-physician relationships, and responsibility for neurosurgical emergencies. Moreover, patients with neurosurgical conditions have unique PC needs given the trajectories of neurosurgical diseases, the realities of prognostication, psychosocial factors, communication strategies, and human behavior. PC improves outcomes among neurosurgical patients. Despite the importance of NPC, neurosurgeons often lack formal training in PC skills, which include identifying patients who require PC, assessing a patient's understanding and preferences regarding illness, educating patients, building trust, managing symptoms, addressing family and caregiver needs, discussing end-of-life care, and recognizing when to refer patients to specialists. The future of NPC involves increasing awareness of the approach's importance, delineating priorities for neurosurgeons with regard to NPC, increasing emphasis on PC

skills during training and practice, expanding research efforts, and adjusting reimbursement structures to incentivize the provision of NPC by neurosurgeons. **Abstract:** <https://bit.ly/3e2qwFo>

The Evolving Specialty of Neuropalliative Care

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Blog – 15 November 2021 – The focus of this posting is on the evolving specialty that is neuropalliative care with summaries of a representative sample of journal articles on the subject published during the past year or so. Included are articles on Parkinson's disease, amyotrophic lateral sclerosis, multiple sclerosis, motor neurone disease, Huntington's disease, dementia, epilepsy and neuro-ICU (neurosciences intensive care unit). There is a short selection of articles on neuropalliative care in the context of the COVID-19 pandemic, from the family caregivers' perspective, and advance care planning (including advance directives and goals-of-care). <https://bit.ly/3cdwyfS>

N.B. This posting is part of a series on neuro-palliative care developed in partnership with the EAPC Neurology Reference Group: <https://bit.ly/3rqe50A>



Progress update: Palliative care development between 2017 and 2020 in five African countries

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 December 2021 – In the mid-2000s, palliative care (PC) pioneers in these five countries (i.e., Kenya, Rwanda, South Africa, Tanzania, and Uganda), supported by Open Society Foundations, began to train healthcare providers and engage policy-makers to ensure that people with life-limiting illnesses and their families had access to appropriate services and essential medicines. In the late 2010s, it embraced an approach that mixed strategic communications and advocacy for inclusion of PC into universal health coverage with technical assistance. By the mid-2010s, a vibrant PC community existed that worked closely with governments to develop PC policies, train providers, and ensure access to morphine. By 2021, Kenya and Rwanda had made significant progress scaling up PC services as part of the public healthcare system, and Uganda's government had instructed public hospitals to start providing these services. In South Africa and Tanzania, governments had yet to commit to publicly funded PC services. The experiences in these countries suggest that mixing advocacy, communications, and technical assistance can lead to substantial progress for patient access although full inclusion in universal health coverage remained uncertain in all but Rwanda. **Abstract (w. references):** <https://bit.ly/3eyZANM>

Dying with assistance: The call for an inquiry, the power of a declaration, the role of evidence

MEDICAL LAW REVIEW | Online – 20 December 2021 – The article analyses recent legal challenges of the prohibition of assisted suicide in England and Wales to review where we are in the debate for reform, and where we can go. The article, principally, advocates for an evidence-based new governmental inquiry. Aside the fact that this is widely-supported by various interested parties, this argument stems from the approach recently attempted by claimants in English courts in challenging the prohibition of assisted suicide, and that is, an evidence-based approach to judicial review. As this article discusses, the review of “the available evidence” is unlikely to be done by English courts, but what this new legal strategy does is to send a strong message to Parliament and the government that there is a need to identify and examine the evidence. The findings of a fresh governmental inquiry, will allow Parliament to engage in a careful, informed review of the law and practice on assisted suicide and decide whether there is another way to protect the vulnerable, while respecting individual choice. The benefits of this inquiry go beyond England and Wales; an English (or indeed U.K.-wide) inquiry will inform discussions currently taking place elsewhere, and vice versa. **Full text:** <https://bit.ly/3qa3DWh>

The impact on emotional well-being of being a palliative care volunteer: An interpretative phenomenological analysis

PALLIATIVE MEDICINE | Online – 30 December 2021 – Being a palliative care volunteer impacted on emotional well-being. Positive impacts included feeling “it’s where I’m meant to be” and “the importance of connection.” It enhanced the volunteers’ lives in a variety of ways. “Managing death” could have a positive impact as it helped participants to understand their beliefs about life and death thus contributing to personal development, however, they also had to find ways to manage patients’ fears about death. Negative impacts included challenges and frustrations that the role brought: “it can be challenging.” Difficult experiences were central to volunteers’ experience of their roles. Challenging experiences, which these findings support, can include seeing suffering, particularly in younger patients, time constraints for volunteers, not feeling confident in communicating with patients and how well volunteers’ felt they were fulfilling their role. Additionally, challenges of “not being good enough,” not being able to do “enough” for patients and challenges regarding the hospice and its processes were identified. Policymakers and practitioners should consider working with volunteers to discuss helpful coping mechanisms, where they might seek professional support and channels that could be accessed to discuss patients with whom they are struggling. This could include input from the multi-disciplinary team, identify gaps in knowledge and availability of support and could be addressed from induction. Reflective practice groups, run by clinical psychologists, could be useful for volunteers to discuss patients, families, difficulties and any aspects of the therapeutic relationship. **Full text:** <https://bit.ly/3ESiWs9>

Teaching about death and dying: A national mixed-methods survey of palliative care education provision in Swedish undergraduate nursing programmes

SCANDANAVIAN JOURNAL OF CARING SCIENCES | Online – 28 December 2021 – With an increasing need for palliative care (PC) worldwide, registered nurses need to be prepared for the complexity of PC and end-of-life care (EoL) and, hence, there is a need for a substantial foundation in education in this area. It is therefore notable that only a few of the universities in Sweden include a compulsory course about PC and EoLC in their syllabus, and that this is up to the universities themselves to decide. Lecturers strive to increase the content of the education about PC in undergraduate nursing programmes with new innovative pedagogical methods, although they also have to compete with other topics in the educational programme. The PC education provision at the different universities included a variety of pedagogical methods, with lectures and seminars being the most commonly used, and clinical visits and simulated training the least frequently used. The most challenging aspect for students, as experienced by the lecturers, was to provide an understanding of the PC approach, address any existential concerns and promote good communication with the patients. Although lecturers strived to develop pedagogical methods to improve the students’ understanding of PC, there is still a shortage of learning related to PC in clinical education that includes sensitive guidance from lecturers and clinically experienced nurses. **Full text:** <https://bit.ly/34aXjXn>

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Related:

- *ADVANCES IN MEDICAL EDUCATION & PRACTICE* | Online – 30 December 2021 – ‘**Spiralled palliative care curriculum aligned with international guidelines improves self-efficacy but not attitudes: Education intervention study.**’ In this study, the benefit of dedicated teaching time which focused on identification of the dying patient, symptom management and communication was obvious and measurable. The exposure, however, to patients varied widely and appeared to be worsening through the study period. This study suggests undergraduate palliative medicine curricula should focus on teaching the concepts and content of end-of-life care, but also provide several opportunities to experience the care required for a quality death. **Full text:** <https://bit.ly/3FLiT2A>

Family members’ participation in palliative inpatient care: An integrative review

SCANDANAVIAN JOURNAL OF CARING SCIENCES | Online – 27 December 2021 – Family members’ participation in hospital inpatient palliative care consists of participation in different aspects of patient care, concerning physical, emotional and practical care and also decision-making. This participation depends on the needs of the patient, varies between each family member, and is affected by the hospital environment and the way healthcare professionals (HCPs) acknowledge their role. Participation offers support to the patient, promotes good patient care and could also enhance the coping of patients and family members at home. Active participation in the care is a way for family members to offer their support and to ensure that the patient receives good care and that their needs are being met. HCPs in clinical settings should support family members’ participation in different ways and also educate them about the possibilities to participate. Research concerning family members’ participation in hospital inpatient care is still scarce. Less than half of the included studies examined family members’ and patients’ experiences; therefore, future research is still needed from different perspectives concerning different aspects of care. Also, intervention research is needed concerning support provided for family members’ participation. **Full text:** <https://bit.ly/3euv2N5>

Research Matters

Administrative data for palliative care research: Friend or foe?

ANNALS OF THE AMERICAN THORACIC SOCIETY, 2022;19(1):5-7. Patients with chronic obstructive pulmonary disease (COPD) receive palliative care (PC) far less often than those with cancer, despite having comparable or greater needs. Many have called for earlier and more frequent PC in COPD, which has strong face validity in clinical practice, yet the evidence base in this population is less robust than that in those with cancer or heart failure. Thus, the benefits of PC in COPD and other understudied chronic diseases are commonly inferred from the evidence that exists in these other populations. Although this “one-size-fits-all” approach may enable more rapid progress in increasing PC for these vulnerable populations, it also risks using a scarce resource in an inefficient and potentially ineffective manner. Maclagan and colleagues report results from the largest study to date examining the effects of PC in COPD.¹ By using health administrative databases from Ontario, Canada, they examined the association between receipt of PC and days alive at home per person-year through at least 1 year or death among patients who had their second or later COPD-related hospitalization between April 2010 and March 2017. Among the more than 35,000 patients with advanced COPD included in this cohort study, 1,788 (5%) received PC. Patients who received PC died at a higher rate and were more likely to die at home, although the latter difference disappeared in a sensitivity analysis in which patients who died in nursing homes were included as at-home deaths. **Full text:** <https://bit.ly/3qHKriK>

1. ‘Association of palliative care with days at home and healthcare use in patients with advanced chronic obstructive pulmonary disease: A cohort study,’ *Annals of the American Thoracic Society*, 2022;19(1):48-57. **Abstract:** <https://bit.ly/3zdn7gR>

N.B. Search back issues of Media Watch for additional articles on PC for patients with “COPD” at: <http://bit.ly/2ThijkC>

Co-design of an evidenced informed service model of integrated palliative care for persons living with severe mental illness: A qualitative exploratory study

HEALTHCARE, 2021;9(12):1710. There is currently a dearth of evidence in relation to understanding the palliative care (PC) needs of people with severe mental illness and how future care delivery can be designed to both recognise and respond to those needs. This study aims to co-design an evidenced informed service model of integrated PC for persons living with a severe mental illness. Methods: This qualitative sequential study underpinned by interpretivism will have six phases. An expert reference group will be established in Phase 1, to inform all stages of this study. Phase 2 will include a systematic literature review to synthesise current evidence in relation to PC service provision for people with severe mental illness. In Phase 3, qualitative interviews will be undertaken with both, patients who have a severe mental illness and in receipt of PC, and bereaved caregivers of people who have died 6-18 months previously with a diagnosis of severe mental illness, across two recruitment sites in the U.K. Focus groups with both mental health and PC multidisciplinary staff will be undertaken across the two recruitment sites in Phase 4. Phase 5 will involve the co-design of a service model of integrated PC for persons living with severe mental illness. Phase 6 will develop practice recommendations for this client cohort. PC needs to be available at all levels of care systems; it is estimated that, globally, only 14% of patients who need PC receive it. Reducing inequalities experienced by people with severe mental illness is embedded in the National Health Service Long Term Plan. Internationally, the gap between those with a mental illness needing care and those with access to care remains considerable. Future policy and practice will benefit from a better understanding of the needs of this client cohort and the development of a co-designed integrated care pathway to facilitate timely access to PC for people with a severe mental illness. **Full text:** <https://bit.ly/3e5pecC>

Noted in Media Watch 25 October 2021 (#740, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 21 October 2021 – ‘**Adapting the collaborative care model to palliative care: Establishing mental health-serious illness care integration.**’ Models of palliative care-specialist serious illness care integration have allowed a greater number of people to enjoy the benefits of palliative care (PC). Mental health integration is the next frontier in providing holistic care to individuals living with serious illnesses. Models of mental health-medical integration ... are attractive means by which to achieve mental health integration because they have been used effectively to improve mental health service delivery in primary care and other medical settings; they have also been adapted to PC integration with oncology and other medical fields. **Full text:** <https://bit.ly/3B2hJfN>

Noted in Media Watch 6 September 2021 (#733, p.12):

- *PALLIATIVE MEDICINE* | Online – 3 September 2021 – ‘**End-of-life care for people with severe mental illness: Mixed methods systematic review and thematic synthesis.**’ This rigorous, mixed methods, systematic review and thematic synthesis has brought together research from 10 countries, plus exemplar policy and guidance from the four nations of the U.K., in an important but neglected area. Beyond people with severe mental illness, findings have relevance for the end-of-life care (EoLC) of other disadvantaged groups for whom health inequalities persist. With regards to future work, EoLC for people with severe mental illness is a wide-open area for well-designed research, including intervention studies of which no examples were found meeting the inclusion criteria for this review. **Full text:** <https://bit.ly/3tfatuB>

Handling missing data and drop out in hospice/palliative care trials through the estimand framework

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 22 December 2021 – Missing data are common in hospice/palliative care (PC) randomised trials due to high drop-out because of the demographic of interest. It can introduce bias in the estimate of the treatment effect and its precision. The International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use (ICH) released updated guidance on statistical principles for clinical trials introducing the estimand framework to align trial objectives, trial conduct, statistical analysis and interpretation of results. The authors of this article outline the estimand framework by highlighting five elements of an estimand: 1) Treatment; 2) Population; 3) Vari-

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able; 4) Summary measure; and, 5) Intercurrent event handling. They list common intercurrent events in PC trials and present the five strategies for handling intercurrent events outlined in the ICH guidance. When planning a PC trial, the estimand should be explicitly stated, including how intercurrent events will be handled in the analysis. This should be informed by the scientific objectives of the trial. The estimand guides the handling of missing data during the conduct and analysis of the trial. Defining an estimand is not a statistical activity, but a multi-disciplinary process involving all stakeholders. **Abstract (w. references):** <https://bit.ly/3JgL5fD>

Reflections on including patients in a randomized placebo-controlled multicentre trial in the dying phase: The SILENCE study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 22 December 2021 – A need exists for studies investigating symptom relief at the end of life (EoL). Randomised controlled trials (RCTs) are the gold standard for demonstrating efficacy of medication, but they are difficult to perform at the EoL due to barriers such as the vulnerability of patients and gatekeeping by healthcare professionals. The authors of this article analysed and reflected on recruitment, participation, and strategies used in an RCT at the EoL. The SILENCE study, performed in six inpatient hospice facilities, was a placebo-controlled trial... The authors addressed patients' vulnerability by using an advance consent procedure, and potential gatekeeping by extensive training of healthcare professionals and the appointment of hospice doctors as daily responsible researchers. In almost 3 years, 1,097 patients were admitted of whom 626 were eligible at first assessment. Of these, 119 (19%) dropped out because of physical deterioration before they could be informed about the study (44) or sign informed consent (75). Twenty-five (4%) patients were not asked to participate. In 24 cases (4%), relatives advised against the patient participating. Overall, 229 patients (37%) gave informed consent to participate. The vulnerability of patients was the most important barrier in this medication study at the EoL. Gatekeeping by healthcare professionals and relatives occurred in a small number of patients. The robust design and applied strategies to facilitate patient recruitment in this study resulted in a successful study with sufficient participants. **Abstract (w. references):** <https://bit.ly/3yWeZRK>

Publishing Matters

Membership of the editorial boards of journals published by the predatory publisher OMICS: Willing and unwilling participation

INFORMATION RESEARCH (University of Borås, Sweden), 2021;26(4):9112. OMICS is the largest and most successful predatory publisher, with numerous subsidiaries. In 2019 it was convicted of unethical publishing practices. A numerical tally of OMICS's editorial listings was compiled across 131 nations. Names and affiliations were recorded for seven nations. A sample was surveyed to estimate the proportions of those aware and unaware of their listing, and of OMICS's conviction. OMICS has twenty subsidiaries and 26,772 editor (and editorial board) listings, 11,361 from just seven nations. Proportional to population, Greeks were most frequently represented on OMICS's editorial boards, followed by Americans, Singaporeans and Italians. In absolute terms, Americans were the most numerous. The survey found that more than half of the respondents were either unaware of their listing or were unwilling to be listed, and 26% were unaware of OMICS's conviction. OMICS's editorial boards do not function as they do for respectable publishers, hence the information published in OMICS journals is unreliable. Academic alliances with OMICS are potentially damaging to academic careers and institutional reputations. Universities should develop policies dealing with predatory publishers in general, OMICS in particular. **Full text:** <https://bit.ly/3z76TG8>

N.B. OMICS publications include the *Journal of Palliative Care & Medicine*: <http://bit.ly/2TVQkXv>

[Media Watch: Access on Online \[Updated 12.31.2021\]](#)

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3IH8oz0>

[Scroll down to 'Media Watch: a Potpourri']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

Asia



Asia Pacific
Hospice Palliative
Care Network

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

[Scroll down to 'Media Watch']

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



BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION <https://bit.ly/3two4xX>

[Grief & Bereavement & Mental Health Summit 2021 'Resource Page.' Scroll down to 'International Palliative Care Resource Center']



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

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

ONTARIO | Acclaim Health: <https://bit.ly/3g82uuS>

[Scroll down to 'General Resources' and 'Media Watch']

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

ONTARIO | Mississauga Halton Palliative Care Network: <https://bit.ly/3tby3b3>

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://bit.ly/3wvL5RW>

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

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

[Media Watch: Editorial Practice](#)

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Cont.

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