

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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To build a system of end-of-life care that connects health services with community services, and formal care with informal care, further development of palliative care linkages with primary care and aged care, and with civic programs that mobilise and nurture compassionate care in local communities is needed.

'Palliative and end-of-life care service models: To what extent are consumer perspectives considered?' (p.7), in *Healthcare*.

U.S.A.

Obstacles persist for rural patients to access hospice

HOSPICE NEWS | Online – 28 September 2021 – Demand for hospice and palliative care is rising in rural areas as they are for the rest of the country, but patients in those regions often lack access to care. Hospices trying to reach them often contend with lower patient volume and long travel times between home visits. About 82% of hospices operated in urban or suburban areas in 2019, according to the Medicare Payment Advisory Commission. Only 18% work in rural areas. This is not necessarily an indicator of access, as these data do not account for the size of those providers or their capacity to serve patients. Nevertheless, the commission indicated that the proportion of Medicare decedents who elect hospice is rising, and the number of provided available to serve them is shrinking. The limited options for rural patients who need hospice care reflects the broader issue of healthcare disparities throughout the continuum... Despite the relatively low

population density, rural America has a high concentration of seniors. About 1-in-5 adults age 65 or older dwell in a rural area, according to the U.S. Census Bureau. This represents more than 17% of the total rural U.S. population. In some states, such as Vermont and Maine, rural seniors accounted for 65.3% and 62.7%, respectively. <https://bit.ly/3mfpVnk>

Specialist Publications

'Social determinants of health may predict end of life Portable Orders for Life Sustaining Treatment form completion and treatment selections' (p.5), in *American Journal of Hospice & Palliative Medicine*.

'Hospice acquisitions by profit-driven private equity firms' (p.8), in *JAMA Health Forum*.

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Related:

- *KAISER HEALTH NEWS* | Online – 30 September 2021 – ‘**COVID is killing rural Americans at twice the rate of urbanites.**’ Rural Americans are dying of COVID at more than twice the rate of their urban counterparts – a divide health experts say is likely to widen as access to medical care shrinks for a population that tends to be older, sicker, heavier, poorer and less vaccinated. While the initial surge of COVID-19 deaths skipped over much of rural America, where roughly 15% of Americans live, non-metropolitan mortality rates quickly started to outpace those of metropolitan areas as the virus spread nationwide, according to data from the Rural Policy Research Institute.¹ About 1 in 434 rural Americans have died of COVID, compared with roughly 1 in 513 urban Americans. <https://bit.ly/3opBnj4>

N.B. Link to Rural Policy Research Institute embedded in *Kaiser Health News* article.

Noted in Media Watch 3 May 2021 (#715, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 28 April 2021 – ‘**Examining barriers and facilitators to palliative care access in rural areas: A scoping review.**’ Access to palliative care (PC) remains challenging for rural Americans... Given the demand and benefits of PC, a comprehensive view of PC access would inform policymakers in developing PC services in rural areas. The findings of this review highlight the need for funding support to increase provider competency, service availability and accessibility, and the public knowledge and awareness of PC in rural areas. A holistic and tailored PC model that standardizes care delivery, referral and coordination, including family caregiver support programs, can improve care access. **Abstract (w. references):** <https://bit.ly/2R0dsIp>

N.B. Selected articles on the provision and delivery of hospice and PC services in rural America noted in Media Watch 7 September 2020 (#682, p.4).

Dying prisoners deserve dignity and palliative care, if not compassionate release

MARYLAND | *The Baltimore Sun* – 28 September 2021 – There is an urgent need to ensure access to quality palliative medicine, if not compassionate release, for incarcerated prisoners with advanced illness, a disproportionate percentage of whom are economically disadvantaged and from communities of color. Our system continues vacillating between compassion for alleviating human suffering and punishment. Responding to the needs of dying prisoners will take a variety of approaches, none of which is easy. The California Medical Facility [for example] has successfully incorporated prisoner volunteers into a peer support program with training in the psychosocial and spiritual dimensions of end-of-life care. Physicians have a moral obligation to speak up about the importance of compassion, dignity and safety for all especially our most marginalized, vulnerable populations. Indeed, promoting social justice in this manner allows us to care for the health and well-being of people we are privileged to serve. <https://bit.ly/3igico2>

N.B. End-of-life care in prisons 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 is available by way of a ‘Backgrounder,’ last updated 1 August 2021. Articles on compassionate release in the U.S. are noted on pp.3-4. **Downloaded at the Palliative Care Network website:** <http://bit.ly/2RdegnL>



LEAVE NO ONE BEHIND
EQUITY IN ACCESS TO PALLIATIVE CARE

World Hospice and
Palliative Care Day | **9 OCTOBER 2021**

www.thewhpc.org/world-hospice-and-palliative-care-day

International

Governments should follow Moldova's lead and ensure universal access to palliative care

OPEN SOCIETY FOUNDATIONS | Online – 1 October 2021 – In the 1990s, responding in part by the experience of seeing the deaths of both of his own parents from cancer, George Soros launched an effort to change the way the medical establishment responded to pain and terminal illness in the U.S. This new palliative care (PC) approach involved making the control of pain a key priority of treatment and sought to address all needs – not just the purely medical – of a patient reaching the end of life or experiencing serious illness. In the early 2000s, the Open Society Foundations expanded this work to other parts of the globe, including in the former communist countries of East and Central Europe. In several of those countries, including Albania, Romania, Hungary, and Moldova, funding from Open Society and others, such as the Britain's Sue Ryder Trust and Hospices of Hope, helped kick-start dramatic changes in public health approaches. In Moldova, we have seen important progress,

starting with the inclusion of the provision of PC as an element of the country's overall public health strategy. Over the years, training and education programs for doctors and nurses through basic and continuous education have become mandatory; the number of PC providers has grown; and essential medicines that assist with pain management have become available for both adults and children. <https://osf.to/2Y9mWVs>

Specialist Publications

'Access to palliative care reimaged' (p.6), in *Future Healthcare Journal*.

'An online international comparison of palliative care identification in primary care using the "surprise" question' (p.7), in *Palliative Medicine*.

More than 70,000 extra deaths at home in England and Wales since pandemic began

U.K. (England & Wales) | *The Evening Standard* (London) – 28 September 2021 – Extra deaths – known as "excess deaths" – are the number of deaths above the average for the corresponding period in the non-pandemic years of 2015-2019. A total of 70,602 excess deaths in homes in England and Wales were registered between 7 March 2020 and 17 September 2021, according to ... analysis of data from the Office for National Statistics (ONS).¹ Analysis published earlier this year by the ONS found that, while the majority of deaths due to COVID-19 in 2020 happened in hospitals and care homes, many deaths from other causes, such as breast cancer and prostate cancer, happened in private homes of people who – in a non-pandemic year – may have typically died elsewhere such as in hospital. Ruth Driscoll, head of policy and public affairs at end-of-life (EoL) charity Marie Curie, said: "This latest data shows that during the pandemic, on average, over 120 more people were dying at home every day compared with the previous five years. This trend is not going away and these figures continue to point to a hidden crisis happening in people's homes up and down the country. People are dying at home without access to pain relief or the dignity they deserve, and their carers are being left unsupported. Lessons must be learned from the pandemic, which has been a stress test for EoL in the community and has shown that the current model for supporting people at EoL is neither resilient nor sustainable in the long term. <https://bit.ly/2ZvKG6D>

1. 'Care home resident deaths registered in England and Wales...', Office for National Statistics, 28 September 2021. <https://bit.ly/39ODSDe>

Noted in Media Watch 6 September 2021 (#733, p.3):

- U.K. | *The Financial Times* – 31 August 2021 – '**Rise in U.K. deaths at home during pandemic raises questions about support and treatment.**' Swelling the numbers able to die in familiar surroundings, with loved ones at their side, has long been a goal of compassionate healthcare. But some fear that a sharp rise in the number of deaths at home during the 18 months of the pandemic is masking a bleaker story, raising questions about whether some have ended their lives without the right level of support or even died unnecessarily for lack of treatment. The rise in the number dying at home has been one of the most striking, but little remarked, phenomena of the pandemic. A shortage of resources is at least part of the story... <https://on.ft.com/3DMymyP>

Specialist Publications

Palliative surgery

AMA JOURNAL OF ETHICS, 2021;23(10):E757-831. Palliative care (PC) is not just for dying patients. In fact, dying patients are living patients, and all patients deserve palliation. Contrary to popular belief among many patients and clinicians, palliative interventions can be invasive and include not only medical, but surgical care. In any case, PC should be defined by intention: partnering clinicians, patients, and their loved ones aim neither to cure disease nor to prolong life, but to improve the quality of a patient's life at any needed time. Quality of life is motivated by goal-elucidating conversation, counseling, and symptom management-directed intervention. This issue of the journal investigates surgical palliation specifically, with sharp focus on intention formation and trust preservation. **Journal contents page:** <https://bit.ly/3ip1Nh8>

Research Matters

'Defining ethical challenge(s) in healthcare research: A rapid review' (p.13), in *BMC Medical Ethics*.

'Traumatic grief research and care in the aftermath of the COVID-19 pandemic' (p.13), in *European Journal of Psychotraumatology*.

Publishing Matters

'Ten simple rules for avoiding predatory publishing scams' (p.13), in *PLOS Computational Biology*.

'Profile of authors publishing in "predatory" journals and causal factors behind their decision: A systematic review' (p.14), in *Research Evaluation*.

N.B. Selected articles on PC in surgery noted in Media Watch 9 August 2021 (#729, p.10).

The role of specialty palliative care for amyotrophic lateral sclerosis

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 September 2021 – Amyotrophic lateral sclerosis (ALS) is a progressive and incurable neurodegenerative disease resulting in the loss of motor neurons, eventually leading to death. ALS results in complex physical, emotional, and spiritual care needs. Specialty palliative care (SPC) is a medical specialty for patients with serious illness that provides an extra layer of support through complicated symptom management, goals-of-care conversations, and support to patients and families during hard times. The authors focuses on several key areas of SPC for ALS including insurance and care models, advance care planning, symptom management, quality of life, caregiver support, and end-of-life care. Recommendations to improve SPC for patients with ALS are reviewed in the discussion section. **Abstract (w. references):** <https://bit.ly/3idHWkU>

N.B. Search back issues of Media Watch for additional articles on "ALS" and also "neuropalliative" at: <http://bit.ly/2ThijkC>

The role of an inpatient hospice and palliative clinical pharmacist in the interdisciplinary team

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 September 2021 – Current national consensus developed by palliative care (PC) experts recommends the inclusion of pharmacists in an interdisciplinary team to provide quality PC. However, national registry data report that less than 10% of inpatient palliative teams in the U.S. have a clinical pharmacist. Clinical pharmacists have an impactful role in palliative patients' quality of life by optimizing symptom management, deprescribing, and providing education to the PC team as well as patients and their families. In this report, the authors review the current literature on the role of a palliative pharmacist in an inpatient PC setting and compare and contrast this with their own clinical practice, providing case examples about the role of a palliative clinical pharmacist in an interdisciplinary inpatient PC setting. Future strategies are needed to increase post-graduate specialized pharmacy residency training in PC as well as education on palliative and hospice care in pharmacy schools to support the role of clinical pharmacists in PC. **Abstract (w. references):** <https://bit.ly/3AUWUn4>

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Noted in Media Watch 26 April 2021 (#714, p.9):

- *INTERNATIONAL JOURNAL OF PHARMACY PRACTICE* | Online – 17 April 2021 – ‘**A national survey of hospice pharmacists and a comparison with international models.**’ Pharmacists can contribute to improved patient outcomes, improve medicine knowledge, reduce drug costs, and minimise errors. However, their role within hospice-based services is not well described. Most U.K. hospices have access to pharmacy support; however, much of this falls below recommended levels. U.K. hospice pharmacists carry out multiple clinical duties, despite having limited access to patient records. Many reported ... an appetite for pharmacist-specific PC training... Sources of hospice medicines vary, and this could have cost implications for hospices... **Full text:** <https://bit.ly/2RFJObH>

Social determinants of health may predict end of life Portable Orders for Life-Sustaining Treatment form completion and treatment selections

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 26 September 2021 – End-of-life (EoL) care planning is important for aging adults given the growing prevalence of chronic medical conditions in the U.S. The Portable Orders for Life-Sustaining Treatment (POLST) program promotes communication between clinicians and patients with advanced illness about EoL treatment preferences. Despite growing resources for EoL care, utilization remains unequal based on social determinants of health (SDOH), including race, language, urbanization, and education. The authors evaluated the relationship between POLST form selections and completion rates and SDOH. Oregon POLST Registry & American Community Survey data from 2013 to 2017 were analyzed retrospectively. 127,588 POLST forms from 319 ZIP codes were included. POLST form completion rates were highest among urban ZIP codes, and urban registrants more often selected CPR and full treatment. ZIP codes with higher incomes tended to select CPR. ZIP codes with higher rates of private insurance completed POLST forms, and selected CPR and full treatment more frequently. ZIP codes with higher rates of Bachelor’s degrees (or higher) completed POLST forms and selected full treatment more frequently. Various SDOH-specifically, urbanization, insurance status, income level and educational level achieved-may influence POLST form completion rates and selections. The expanding socioeconomic diversity and growth of urban communities, highlight the need for broader access to EOL planning and POLST. **Abstract (w. references):** <https://bit.ly/3idpetH>

Noted in Media Watch 27 September 2021 (#736, p.12):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 22 September 2021 – ‘**The influence of POLST on treatment intensity at the end of life: A systematic review.**’ Despite its widespread implementation, it is unclear whether Physician Orders for Life-Sustaining Treatment (POLST) are safe and improve the delivery of care that patients desire. Among 104,554 patients across 20 observational studies, 27,090 had POLST. No randomized controlled trials were identified. The authors found moderate strength of evidence that treatment limitations on POLST may reduce treatment intensity among patients with serious illness. However, the evidence base is limited and demonstrates potential unintended consequences of POLST. **Abstract:** <https://bit.ly/3hYBwpH>

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

Multidisciplinary team meetings in palliative care: An ethnographic study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 30 September 2021 – Multidisciplinary team meetings (MDTMs) are a regular feature in the provision of palliative care (PC), involving a range of professionals. Yet, their purpose and best format are not necessarily well understood or documented. This article describes how hospital and community-based PC multidisciplinary team meetings operate to elucidate some of their main values and offer an opportunity to share examples of good practice. There are several recommendations from the authors’ observations. The space where a meeting is held often matters more than may be realised; this was noticed by the teams especially after doing online meetings (after data collection finished). Not only can it impact contributions and collegiality but also can impact the value accorded to the meetings. An agreed format and prescribed timings help convey expectations while also ensuring that the

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meeting does not overrun; however, some flexibility is essential in order to respond to specific issues and concerns that can be raised during the course of discussion. Documenting action plans during the meeting, rather than after, improves record-keeping and ensures that staff are clear about what has been decided. Varying who fills in the documentation can share workload and build confidence with using clinical and/or administrative codes. Ongoing discussion about the format, outcome and experience of meetings can help align meeting activities with team objectives and strengthen interprofessional relationships. The total value of MDTMs can only be appreciated by recognising the wide range of additional aspects, beyond merely the clinical and social support decisions that are officially recorded. **Full text:** <https://bit.ly/3ijSwH6>

Palliative care interventions in advanced dementia

COCHRANE DATABASE OF SYSTEMATIC REVIEWS | Online – 28 September 2021 – The evidence on palliative care interventions in advanced dementia is limited in quantity and certainty. When compared to usual care, changes to the organisation and delivery of care for people with advanced dementia may lead to improvements in comfort in dying, but the evidence for this was of very low certainty. Advance care planning interventions, compared to usual care, probably increase the documentation of advance directives and the occurrence of discussions about goals-of-care (GoC), and may also increase concordance with GoC. The authors did not detect other effects. The uncertainty in the evidence across all outcomes in both comparisons is mainly driven by imprecision of effect estimates and risk of bias in the included studies.

Abstract: <https://bit.ly/2Y22kPj>

N.B. Search back issues of Media Watch for additional articles on people palliative care for people living with dementia and also “neuropalliative” at: <http://bit.ly/2ThijkC>

Access to palliative care reimagined

FUTURE HEALTHCARE JOURNAL | Online – 23 September 2021 – Access to palliative care (PC) is commonly considered as solely a health services challenge rather than a community challenge. Successive healthcare reports continue to pose the question of access and its solution in terms that ask what a service can do rather than what an ally a service can become. However, the question is not what can we do for disadvantaged communities, but rather, what can we do together with them as fellow providers of PC. The first part of this article reviews the most common recommendations offered for increasing access to PC. The second part advocates an alternative way to address this challenge by employing the key practice methods of a new public health/health promotion approach to PC. **Full text (click on pdf icon):** <https://bit.ly/2Wih5wi>

Doctors’ views on how to improve communication and quality of care for patients experiencing end-of-life: A qualitative descriptive study

HEALTHCARE | Online – 29 September 2021 – This research adds to a growing body of evidence highlighting the challenges needed to overcome [and] to improve communication and quality of care for patients experiencing end-of-life (EoL). It extends this by setting out suggestions for improvements, as identified by the doctors interviewed. This study demonstrates the need for better communication and coordination between professionals in various settings, to better understand, promote and utilise available assets and resources (including knowledge, advice, training and other opportunities for learning, e.g., from palliative care teams and hospices, those in paediatrics, and varying levels of seniority) across the sector as well as about individual patient-centred care. It outlines implications for the system as a whole – a need to work more effectively across the system, for more guidance at a strategic level and processes to be put in place to support this and to help staff in both acute and primary care to “be brave” in discussing and providing EoL care. **Full text:** <https://bit.ly/2YcfcBz>

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Would the *Healthcare* article be of interest to a colleague?

Related:

- *PALLIATIVE MEDICINE* | Online – 1 October 2021 – ‘**An online international comparison of palliative care identification in primary care using the “surprise” question.**’ The “surprise” question (‘Would I be surprised if this patient died within 12 months?’) identifies patients in the last year of life. In this study, participating general practitioners (GPs) located in Belgium, Germany, Italy, The Netherlands, Switzerland and U.K. completed 20 hypothetical patient summaries (“vignettes”). There was a significant difference in how GPs in different countries responded... The overall threshold level of surprise was an estimated probability of death within the next year of 49.8%, at which point “Yes, I would be surprised” typically became “No, I would not be surprised.” **Full text:** <https://bit.ly/3A31wq0>

Palliative and end-of-life care service models: To what extent are consumer perspectives considered?

HEALTHCARE | Online – 28 September 2021 – This article presents evidence found in a search of national and international literature for patient preferences concerning settings in which to receive palliative care (PC) and the appropriateness of different models of PC. The purpose was to inform end-of-life care (EoLC) policy and service development of the Western Australian Department of Health through a rapid review of the literature. It was found that consumer experience of PC is investigated poorly, and consumer contribution to service and policy design is limited and selective. Most patients experience a mix of settings during their illness, and evidence found by the review has more to do with qualities and values that will contribute to good EoLC in any location. Models of care do not make systematic use of the consumer data that are available to them, although an increasingly common theme is the need for integration of the various sources of care supporting dying people. It is equally clear that most integration models limit their attention to EoLC provided by health services. Transitions between settings merit further attention. The authors argue that models of care should take account of consumer experience not by incorporating generalised evidence but by co-creating services with local communities using a public health approach. **Full text (click on pdf icon):** <https://bit.ly/3ohiHIK>

Noted in Media Watch 10 April 2017 (#507, p.15):

- *PALLIATIVE MEDICINE* | Online – 5 April 2017 – ‘**What do we know about different models of providing palliative care? Findings from a systematic review of reviews.**’ A wide range of organisational models of palliative care (PC) exist. However, decision-makers need more information about which models are likely to be most effective in different settings and for different patient groups. Much of the evidence relates to home-based PC, although some models are delivered across care settings. Reviews report several potential advantages and few disadvantages of models of PC delivery. However, under-reporting of the components of intervention and comparator models are major barriers to the evaluation and implementation of models of PC. **Full text (click on enotes.tripod.com icon):** <https://bit.ly/3IEuR51>

Elements of integrated palliative care in chronic heart failure across the care continuum: A scoping review

HEART, LUNG & CIRCULATION | Online – 27 September 2021 – Individuals with chronic heart failure (CHF) experience high symptom burden, reduced quality of life and high healthcare utilisation. Although there is growing evidence that a palliative approach, provided concurrently with usual treatment improves outcomes, the method of integrating palliative care (PC) for individuals living with CHF across the care continuum remains elusive. Seventy-nine (79) articles were selected that described key elements to integrate PC for individuals with CHF. This review identifies four levels of key strategic elements: 1) Clinical; 2) Professional; 3) Organisational; and, 4) System-level integration. Implementing strategies across these elements facilitates integrated PC for individuals with CHF. Inter-sectorial collaborations across systems and the intersection of health and social services are essential to delivering integrated, person-centred PC. Further research focussing on patient and family needs at a system-level is needed. Research with strong theoretical underpinnings utilising implementation science methods are required to achieve and sustain complex behaviour change to translate key elements. **Abstract (w. references):** <https://bit.ly/2ZIMAAZ>

N.B. Selected articles on the role of PC in advanced/chronic heart failure noted in Media Watch 13 September 2021 (#734, p.7) and 6 September 2021 (#733, pp.8-9).

Living, loving and letting go-navigating the relational within palliative care of older people in long-term care facilities: An action research study

INTERNATIONAL JOURNAL OF OLDER PERSON NURSING | Online – 26 September 2021 – This study has identified aspects of care described as living, loving and letting go within the context of registered general nurses and healthcare assistants (HCAs) delivering palliative care (PC) and end-of-life care for residents in long-term care facilities (LTC) facilities. As such, the authors describe and make visible their praxis related to being in relation, an important component of person-centred care. This acknowledges the importance of nurses, HCAs and residents living and embracing life through relationships, engaging in meaningful communication. Delivering care in LTC facilities intrinsically encompasses relational and social aspects in the delivery of PC, acknowledging that the majority of residents who live on the unit will die there. Understanding and accommodating this relational aspect of such everyday care is fundamental to building resilience, particularly related to creating professional development which acknowledges and responds to the context of nurse, healthcare assistant, resident and family relationships and addresses the legacy of staff grief. **Full text:** <https://bit.ly/3CTgAZ5>

N.B. Search back issues of Media Watch for additional articles on PC in “long-term” care at: <http://bit.ly/2ThijkC>

Hospice acquisitions by profit-driven private equity firms

JAMA HEALTH FORUM, 2021 ;2(9):e213745. Profit is a key, driving focus of many businesses (in the U.S.). 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 3 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. Private equity firms see huge profits in buying hospice programs that are providing care for the most vulnerable persons and their families at a sentinel, often tragic time. Just as private equity acquisition throughout medical specialties has surged in recent years, the hospice industry has been found to be fertile ground for private equity firms. The increasing presence of private equity firms in hospice care is concerning in terms of how it affects hospice patients and those who care for them. It is also concerning in terms of how it might affect the next generation of physicians specializing in palliative medicine. **Full text:** <https://bit.ly/3utOHUA>

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>



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.5.

Palliative care principles and anesthesiology clinical practice: Current perspectives

JOURNAL OF MULTIDISCIPLINARY HEALTHCARE | Online – 27 September 2021 – Anesthesiologists and intensivists integrate palliative care (PC) within their daily practice providing symptoms management as well as family counseling. High-quality communicational skills are fundamental for anesthesiologists and intensivists especially when interfacing with surrogate decision-makers in the ICU or with patients in the preoperative setting while discussing goals-of-care. The COVID-19 pandemic has challenged many aspects of PC delivery: reduced family presence within the ICU, communication with families through 'phone calls or video calls, patient–physician relationship mediated by bulky personal protective equipment and healthcare workers physical and psychological distress due to the increased workload and limitations in resources are some of the most evident. Anesthesiologists and intensivists are increasingly facing challenging clinical situations where principles and practice of PC have to be applied. In this sense, increasing knowledge on PC and providing specific training would allow to deliver high-quality symptom management, family counseling and end-of-life guidance in critical care settings. COVID-19 pandemic sets additional difficulties to PC delivery. **Full text:** <https://bit.ly/3zLclYm>

Noted in Media Watch 18 May 2020 (#666, p.12):

- *CANADIAN JOURNAL OF ANESTHESIA* | Online – 11 May 2020 – ‘**End-of-life care in patients with a highly transmissible respiratory virus: Implications for COVID-19.**’ Symptom management and end-of-life care are core skills for all physicians, although in ordinary times many anesthesiologists have fewer occasions to use these skills. The current COVID-19 pandemic has caused significant mortality over a short time and has necessitated an increase in provision of both critical care and palliative care. For anesthesiologists deployed to units caring for patients with COVID-19, this narrative review provides guidance on conducting goals-of-care discussions, withdrawing life-sustaining measures, and managing distressing symptoms. **Full text:** <https://bit.ly/2Aqle68>

Noted in Media Watch 5 August 2019 (#625, p.14):

- *CURRENT ANESTHESIOLOGY REPORTS* | Online – 27 July 2019 – ‘**Pediatric palliative care in the perioperative period.**’ The purpose of this review is to familiarize anesthesiologists with the role of the subspecialty of pediatric palliative care (PC) and its potential contributions to the management of children with complex and life-threatening illnesses, many of whom may present for operative or diagnostic procedures requiring anesthesia. Recent publications highlight the benefits of PC to patients and families experiencing a wide variety of conditions along the continuum from prenatal application to the management of young adults. Retrospective reports highlight improved quality of life, improved symptom control, an impact on place of care... **Abstract (w. references):** <http://bit.ly/2Os4vFX>

Foundations for psychological thinking in palliative care: Frame and foundation

JOURNAL OF PALLIATIVE MEDICINE, 2021;24(10):1439-1435. This is the second article in the journal's psychological elements of palliative care (PC) series. This series focuses on how key concepts from psychotherapy can be used in the context of PC to improve communication and fine tune PC interventions. The authors introduce two foundational concepts: frame and formulation. The *frame* is the context in which care is delivered; it includes concrete aspects of clinical care such as where it takes place, for how long, and with what frequency. It also includes the conceptual aspects of care, including the specific roles of the clinician and the patient, emergency contingencies, and the extent to which emotion is invited within the clinical encounter. Defining and discussing the frame with patients are especially important in PC because of the strong emotions that arise when talking about serious illness and because many patients may not be familiar with PC before they are in care. *Formulation* is the process by which we make judgment-neutral psychological hypotheses to understand the feelings and behaviors of our patients. It is an ongoing, dynamic process whereby as we learn more about our patients, we integrate that data to improve our explanatory model of who they are. This helps us tailor our interventions to meet their unique needs and respect their life experiences, aptitudes, and vulnerabilities. Both concepts are foundational psychological elements of PC; understanding them will prepare readers to continue to the next four articles in the series. **Abstract:** <https://bit.ly/3os2cDa>

The role of hospice and palliative care in supporting and fostering trust among the LGBTQ+ population

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 30 September 2021 – Lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ+) individuals continue to experience differential access, discrimination, and marginalization in healthcare, which places them at risk for worse health outcomes. This may be especially true for older LGBTQ+ individuals, who may experience more mistrust in (and fear of stigmatization by) the healthcare system even as they develop serious medical illnesses. For these reasons, hospice and palliative care (PC) teams will play an increasingly important role in supporting LGBTQ+ individuals throughout the illness trajectory. In order for hospice and PC clinicians to deliver on the field's mission of whole person/caregiver care, the authors recommend that clinicians identify and critically examine their own biases and assumptions, that they intentionally seek out and practice inclusive care strategies, and that they collaborate to foster an atmosphere of trust and respect for all patients. **Full text:** <https://bit.ly/2Yh118h>

Noted in Media Watch 27 September 2021 (#736, p.7):

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 22 September 2021 – ‘**Centering sexual and gender diversity within compassionate communities: Insights from a community network of LGBTQ2S+ older adults.**’ The compassionate communities movement emphasizes the importance of illness, disability, dying, caregiving, and grief across the lifespan and highlights the communal responsibility of caring for one another. There is a need to recognize and incorporate the needs of diverse communities within this movement and research on dying, caregiving and grief. The authors’ findings emphasize the importance of incorporating the voices of diverse sexual and gender identities and promoting health equity within compassionate community initiatives. **Full text:** <https://bit.ly/39y7mFi>

Noted in Media Watch 13 September 2021 (#734, p.10)

- *PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 9 September 2021 – ‘**Palliative care needs, concerns, and affirmative strategies for the LGBTQ population.**’ Barriers to comprehensive palliative care include gaps in competency training for providers, paucity in research studies, variable resource allocation, financial constraints, and non-protective regulatory policies and practices. There are key strategies to mitigate these barriers while providing affirmative and inclusive care toward sexual and gender minorities patients that can create a therapeutic alliance, improved patient and caregiver satisfaction, enhanced quality of life, and overall well-being. A holistic team-based approach coupled with empathic communication and non-judgmental mind-set are fundamental steps... **Full text:** <https://bit.ly/3tulo3C>

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

Parents as advocates for pediatric palliative care

PEDIATRICS | Online – 1 October 2021 – Caring for a child with a serious or life-limiting illness presents many challenges for families and healthcare providers. Through that experience (and, many times, as it ends), parents are compelled to find and make meaning from their ultimate loss and the many losses along the way. In this Advocacy Case Study, the authors describe the experiences that led a bereaved mother to seek to harness the insights from her own family's loss to help support other families facing the challenges and complexities of a child's serious illness. Her family initially established a family foundation to advocate for palliative care (PC). She later partnered with her family's general pediatrician and the American Academy of Pediatrics to educate providers and bring parent voices to healthcare provider discussions. This work eventually led to the development of the Courageous Parents Network, a non-profit focused on making these parent and provider voices widely available to families and providers through a Web-based collection of videos, blogs, podcasts, and printable guides. Through these insights, the organization addresses feelings of isolation, anxiety, and grief. In addition,



Cont.

these voices illustrate the power and benefits of the growing acceptance of pediatric PC practices. Important lessons learned through these efforts include: 1) The power of stories for validation, healing, and understanding; 2) Opportunity to extend the reach of pediatric PC through provider education and skill-building; 3) Critical importance of the parent-provider advocacy collaboration; and, 4) Necessity of market testing and continuous improvement. **Abstract:** <https://bit.ly/3D0DnSR>

N.B. Courageous Parents Network website: <https://bit.ly/3FautEg>

Related:

- *CHILDREN* | Online – 13 September 2021 – ‘**Palliative care in pediatric pulmonology.**’ The effective management of children with end stage lung disease (ESLD) requires a multidisciplinary approach that is both grounded in medical evidence and respectful of both the patient’s and their family’s story. Through the combined use of primary palliation, regular needs assessment, and specialized palliative care consultation, an interdisciplinary team can provide a comprehensive approach to reduce the suffering of both children with ESLD and their caregivers. Ultimately this approach seeks to guide families through the uncertainty of chronic illness, celebrating individual successes, providing support through inevitable difficulties, and ultimately helping patients reach individualized goals. **Full text:** <https://bit.ly/3igPKCm>
- *HOSPITAL PEDIATRICS* | Online – 1 October 2021 – ‘**An interdisciplinary hospital-based committee to improve pediatric bereavement care.**’ The death of a child can significantly jeopardize the physical, psychosocial, and emotional health of surviving parents, caregivers, and family members. Researchers have only recently begun to explore the trajectory of pediatric bereavement care needs. As an ongoing public health concern, healthcare institutions and related organizations must partner with interdisciplinary care providers and bereaved families to design effective and sustainable bereavement supports in their communities. This article describes the development ... of an interdisciplinary bereavement committee at a children’s hospital within an academic medical center. **Abstract:** <https://bit.ly/3kZHyrZ>
- *JOURNAL OF CANCER EDUCATION* | Online – 30 September 2021 – ‘**Palliative care training for pediatric hematology/oncology fellows: A Canadian perspective.**’ The majority of survey participants agreed pediatric hematology/oncology fellows require dedicated palliative care (PC) training. All programs provided some PC education, but 45% of programs offered 3 or fewer hours of training per year. Only 55% of the program directors believed that their trainees had adequate PC skills on completion of training. Fellows perceived a range of PC skills to be important but expressed low levels of comfort across these skills. Many fellows had experienced distress as a result of managing PC clinical situations, and many cited a lack of training as contributing to their distress.. **Abstract (w. references):** <https://bit.ly/3D0BPsc>
- *JOURNAL OF NEUROSCIENCE NURSING* | Online – 28 September 2021 – ‘**End-of-life healthcare service needs among children with neurological conditions: A latent class analysis.**’ At the end of life (EoL), children with neurological conditions have complex healthcare needs that can be met by providing care of their life-limiting conditions concurrently with hospice care... Given the limited literature on concurrent care for children with neurologic conditions, this investigation aimed to identify patterns of non-hospice, healthcare service needs and to assess characteristics of children within each group. Two distinct classes of non-hospice, healthcare service needs emerged among children with neurological conditions at the EoL. The groups had unique demographic profiles. **Abstract:** <https://bit.ly/2WC7AZa>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 28 September 2021 – ‘**Participatory development of a modular advance care planning program in pediatric palliative care.**’ Advance care planning (ACP) supports decision-making about future medical care. A consistent pediatric approach is still missing. This study aimed at developing a pediatric ACP program (pedACP) meeting specific needs of children, parents and professionals. The overall focus of participants in this study was on the children’s quality of life and an individualized interdisciplinary communication process along the disease trajectory. The program was conceptualized in modular design with fixed modules at the beginning ... and at the end... **Abstract (w. references):** <https://bit.ly/3ihR7ka>

“Withstanding ambivalence is of particular importance”: Controversies among experts on dealing with desire to die in palliative care

PLOS ONE | Online – 24 September 2021 – The authors propose that communication about a desire to die (DTD) should be initiated proactively if realized in an open-ended, empathic manner and guided by a sound clinical rationale such as a semi-structured clinical approach. This recommendation is in line with an expert consensus that grounds the recommendation to proactively address DTD in the German palliative care (PC) guideline for patients with incurable cancer.¹ Such conversations among health professionals (HPs) and their patients can be adequate interventions in PC. They can reveal ambivalences, taboos and uncertainties surrounding DTD and even if they cannot all be resolved, they are easier to handle when they are disclosed. The authors’ five most important recommendations for HPs treating patients who (potentially) DTD are: 1) Use of appropriate language and terminology in open communication about DTD; 2) Reflecting taboos and myths surrounding DTD communications and recognizing (potential) resistance against proactively addressing DTD; 3) In case of DTD (re)assessing physical symptom burden and alleviating pain; 5) In case of persistent DTD screening for depression and considering psychiatric counsel; and, 6) In case of persistent and serious requests for assisted suicide acknowledge the request, deepen the conversation, and ensure the appropriate response in light of the national legislation. The authors suggest encouraging public dialogue on a national and international level, and creating spaces for culture-sensitive debates in science, policy, and clinical practice. **Full text:** <https://bit.ly/3i8ZvCM>

1. ‘German Guideline Program in Oncology: Palliative Care Guideline for Patients with Incurable Cancer.’ **Download English language version at:** <https://bit.ly/3ERvK3b>

Noted in Media Watch 26 July 2021 (#727, p.8):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 23 July 2021 – ‘**Why people think they might hasten their death when faced with irremediable health conditions compared to why they actually do so.**’ This study surveys the differences of relatively healthy proponents of end-of-life choices and people with irremediable health conditions having already made the decision to hasten their deaths on what each group considers important in influencing a desire to hasten death. Psychosocial factors were more important than physical ones for both groups; but those contemplating what might influence them to hasten their deaths in the future thought pain and feeling ill would be much bigger factors than they turned out to be for those deciding to do so. **Full text:** <https://bit.ly/3rthc3j>

Noted in Media Watch 22 February 2021 (#705, p.2):

- IRELAND | *The Irish Times* (Dublin) – 18 February 2021 – ‘**Desire to die among older people often transient, study finds.**’ Researchers have found that the “wish to die” among older people living in the community is often “transient” and is strongly linked to depression and feelings of loneliness. A survey of more than 8,100 people aged over 50 ... found that 4% of people surveyed expressed a wish to die. However, almost three-quarters of those who initially expressed this desire did not feel the same when researchers revisited the issue with them two years later. Sixty-percent of those who reported a wish to die had co-existing depressive symptoms while half of those who stated they wanted to die had been diagnosed with depression. <http://bit.ly/2NFwodZ>



[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>

Research Matters

Defining ethical challenge(s) in healthcare research: A rapid review

BMC MEDICAL ETHICS | Online – 29 September 2021 – The results of this rapid review suggest that a common conceptual understanding of the term “ethical challenge(s)” is lacking within empirical bioethical research and that there is a need for researchers in this area to consider what conceptual formulations might be most useful. Again, failure to use definitions of crucial research concepts within empirical bioethics research potentially generates confusion and avoidable bias within research outputs, risking misleading ethical analyses, evaluations, and resulting recommendations. The authors, therefore, hope this review will help stimulate debate amongst empirical bioethics researchers on possible definitional content for such a commonly used term and prompt further discussion and research. Additionally, given the central role of patient and public partnership and involvement in research, further thought should be given to who should be involved in nominating something as a challenge worthy of study. **Full text:** <https://bit.ly/3D12vZP>

Traumatic grief research and care in the aftermath of the COVID-19 pandemic

EUROPEAN JOURNAL OF PSYCHOTRAUMATOLOGY | Online – 22 September 2021 – The authors present an overview of themes, reviewed literature for useful information for clinical practice, and formulated possible future directions in research during the aftermath of the COVID-19 pandemic. First, it is essential to harmonize the prolonged grief disorder (PGD) diagnostic criteria in both the *International Classification of Diseases -11* and *Diagnostic & Statistical Manual of Mental Disorders-TR*. Second, the development of better screening tools and the implementation and dissemination of interventions for the different stages of the development of PGD are needed. Third, there is a paucity of research regarding pharmacotherapy for PGD and there are many potential directions to investigate, especially to target comorbidities such as depression, in combination with psychotherapy or for those who do not respond well to psychological interventions. Fourth, we need to specially focus on the elderly, which is the population for which the pandemic has had the greatest impact. Fifth, the children/adolescent that are confronted with loss during the pandemic must not be forgotten, especially because they might otherwise be also at increased risk for other psychiatric disorders. Lastly, understanding grief and PGD from a causal system perspective where psychological, biological, and social components are combined, might create new ways to intervene to protect the most vulnerable after the loss of a loved one. **Full text:** <https://bit.ly/3zLQnKi>

Publishing Matters

Ten simple rules for avoiding predatory publishing scams

PLOS COMPUTATIONAL BIOLOGY | Online – 23 September 2021 – Scholarly publishing is undergoing massive changes, accelerated by digital modes of sharing knowledge. The most important rule to avoid predatory publishing scams is to accept that there is a continuum of legitimacy in publishing venues. Set aside time to investigate where and how you want your work to join the scholarly conversation. Your answer may change over time, with different research outputs, and as scholarly outlets change. When you contribute as an author, confirm the validity of the literature you cite. When you serve as a peer reviewer or editor, verify that you are not promoting predatory publishing. Take advantage of new tools and resources to evaluate credible publishers. Stay vigilant! Predatory publishers are always adapting to try to stay one step ahead with their scams. Check in with a librarian who, as an information professional, can offer useful insights for your quest to find the right outlet for your research. **Full text:** <https://bit.ly/3B00VXD>



Palliative Care Network

Palliative Care for Everyone, Everywhere

Closing the Gap Between
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Profile of authors publishing in “predatory” journals and causal factors behind their decision: A systematic review

RESEARCH EVALUATION | Online – 25 September 2021 – Intensified pressure to publish is a hallmark of a rapidly evolving higher education field where the faculty of any hue cannot avoid the “publish or perish” treadmill. Growing need to publish more and to do so fast have resulted in the proliferation of pseudo scholarly publications many regards as “predatory.” This article provides a systematic review of research studies on so-called “predatory” publishing, a new but fast-growing area of research, with a particular focus on the awareness of prospective authors about so-called “predatory” publishing, the profile of authors publishing in “predatory” journals and the causal factors encouraging authors to publish in such outlets. It synthesizes the results of research studies on the topic to identify gaps and trends in the existing knowledge-base to guide further research. Results indicate so-called “predatory” articles are authored by scholars from all fields and levels of academic experience rather than by inexperienced scholars only and “predatory” contributions are not limited to developing countries, suggesting geographical location and author experience fail to explain the author profile of “predatory” articles. Findings of this review suggest causal factors include research evaluation policies and publication pressure that emerge from the research environment in which scholars operate authors’ limited capacity to publish in “legitimate” journals and conventions of so-called “predatory” publishers. This indicates meaningful action might address all these factors in combination, rather than focus on them in isolation. **Abstract:** <https://bit.ly/3AQIG7R>

Media Watch: Editorial Practice

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

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5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
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Something Missed or Overlooked?

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

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International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3tw1eqa>

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Asia Pacific
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[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>

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

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <HTTPS://BIT.LY/3WVL5RW>

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

South America

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