

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

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Compiled & Annotated by Barry R. Ashpole

If our analysis tells us something about the transfer of palliative care interventions internationally, it demonstrates that such transfer can be achieved with discrete measurable successes, rather than in ways that fully endorse the intervention in toto.

'International transfer and translation of an end-of-life care intervention: The case of the Liverpool Care Pathway for the dying patient' (p.10), posted on the Wellcome Open Research website.

Canada

Mobile palliative care services bring comfort to Canada's most vulnerable

BRITISH COLUMBIA | *Broadview Magazine* – 13 November 2020 – Victoria's Palliative Outreach Resource Team (PORT) brings medical care directly to people who are homeless and living in poverty. Katie Leahy, a registered nurse, arrives for the patient's checkup by bicycle, wearing a black rain jacket and thick-soled boots for the drizzly weather that's typical in early spring on Vancouver Island. Dr. Fraser Black, having parked his scooter around the corner, meets Leahy at the entrance of an apartment building on the edge of downtown Victoria. Before meeting with their patient, who's staying with a close friend, they discuss her blood work results and how her health has changed from the week prior. Leahy and Black are part of PORT. It's a mobile service that brings medical care directly to people who are homeless and living in poverty with serious, often terminal, illnesses. PORT can also connect clients to specialized health services, mental health supports, faith leaders and more. Their patient, Ille Jocelyn, is dying. She's barely

over 50 years old. When she first went to hospital with cancer in 2016, she'd fallen on hard times. She was going through a messy divorce and didn't have stable housing or a support network. Her cancer left her in unbearable pain, and without consistent healthcare, she was in and out of hospital emergency departments. She spent time sleeping on the streets in downtown Victoria. In 2019, a social worker introduced Jocelyn to Leahy and Black, who both specialize in palliative care. <https://bit.ly/36x9f38>

Specialist Publications

'Advancing palliative care in patients with chronic kidney disease: From ideas to practice' (p.4), in *American Journal of Kidney Diseases*.

'Gaps in hospice and palliative care research: A scoping review of the North American literature' (p.5), in *Journal of Aging Research*.

N.B. Additional articles on palliative care for the homeless in Canada noted in Media Watch 20 April 2020 (#662, p.12).

U.S.A.

Telepalliative care benefits patients, helps staff achieve work-life balance

HOSPICE NEWS | Online – 11 November 2020 – Telehealth utilization has skyrocketed amid the coronavirus pandemic, with hospice and palliative care providers increasingly exploring new avenues of care. Prior to the pandemic, staff burnout was among the factors that helped to drive telehealth forward as it slowly emerged from a few early adopters to become virtually essential during COVID-19. In March of this year the U.S. Centers for Medicare & Medicaid Services (CMS) temporarily expanded the use of telehealth during the federally declared COVID-19 emergency to help patients, families and clinicians practice social distancing. As CMS allowed healthcare providers to bill for telehealth services, the flexibilities propelled virtual care to the forefront, with many hospices ramping up their telehealth platforms to ensure continuity of care while limiting spread of the virus. The coronavirus has continued its grip across the nation, with the U.S. Centers for Disease Control & Prevention reporting 3.66 million new COVID-19 cases and more than 241,000 related deaths. With patients and staff alike falling ill to the virus, the pandemic has weighed heavily on the sustainability of a shrinking workforce. <https://bit.ly/35msOM0>

Noted in Media Watch 26 October 2020 (#689, p.13):

- *CANCER NURSING*, 2020;43(6):429-430. **'How the COVID-19 pandemic could reshape palliative care into high-tech and high-touch care: An ethics of care perspective.'** COVID-19 disrupted palliative care and other healthcare services as health systems were quickly overwhelmed with patients and by public health measures requiring social distancing and restricting face-to-face contact. These challenges have spurred the adoption of digital health (DH) in many health systems across the globe. DH is mainly concerned with the use of routine and innovative forms of information and communications technology to address health needs. DH has become an umbrella term that encompasses eHealth, telemedicine, mobile health (or mHealth)... **Full text:** <https://bit.ly/3kna58c>

N.B. Selected articles on the role of telemedicine in hospice and palliative care noted in Media Watch 19 October 2020 (#688, pp.5-6).



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>

Specialist Publications

“Advance” care planning re-envisioned’ (p.6), in *Journal of the American Geriatrics Society*.

‘Lack of exposure to palliative care training for Black residents: A study of [U.S. medical] schools with highest and lowest percentages of black enrollment’ (p.8), in *Journal of Pain & Symptom Management*.

‘Rapid implementation of eMOLST order completion and electronic registry to facilitate advance care planning: MOLST documentation using telehealth in the COVID-19’ (p.9), in *NEJM Catalyst*.

‘Engaging primary care physicians to refer patients to home-based palliative is challenging and complicated’ (p.9), in *Palliative Medicine Reports*.

A Framework for Integrating Family Caregivers into the Health Care Team

RAND HEALTHCARE | Online – 10 November 2020 – There are about 53 million family and friends providing care and assistance to loved ones in the U.S. Although family caregivers (FCGs) provide a significant portion of health and support services to individuals with serious illnesses, they are often overlooked by U.S. healthcare systems. Fundamental changes are needed in the way we identify, assess, and support FCGs. Recent changes in the U.S. healthcare system and payment models have increased the opportunities to integrate FCGs into care teams. The authors of this study reviewed the literature on the role of FCGs in the coordination of care and conducted interviews with experts from diverse stakeholder groups to better understand the barriers to integrating FCGs into the patient's health

care team and identify ways to mitigate these barriers. The authors identify policy directions and provide recommendations for next steps in assessing, developing and implementing policies to improve the integration of FCGs into care teams.

Download/view at: <https://bit.ly/3klHMpX>

Extract from Rand Healthcare report

Enhancing coordination between FCGs and the formal care team can improve care planning by integrating caregiver expertise into patients' plan of care and preparing FCGs to be surrogate decision-makers at the end of life.

N.B. There is no specific mention in the Rand Healthcare report of hospice or home-based palliative care.

Noted in Media Watch 21 September 2020 (#684, p.11):

- **PALLIATIVE MEDICINE** | Online – 15 September 2020 – **'Are family carers part of the care team providing end-of-life care? A qualitative interview study on the collaboration between family and professional carers.'** Four main themes emerged that describe the quality of the collaboration between family carers and professionals: 1) Respecting family carers both as someone with care needs and as a member of the care team; 2) The continuous availability and accessibility of healthcare professionals; 3) The provision of information and communication including family carer issues; and, 4) The coordination of care between all parties and contextual factors. The dominant experience by family carers was one of missed opportunities across these themes. **Abstract (w. list of references):** <https://bit.ly/2ZCrBNy>

International

Dying “the Buddhist way” gains in hospice centers in the West

GERMANY | Religion News service – 12 November 2020 – There is no single “way of death” in a faith that is the dominant religion across Southeast Asia and Japan, and rites vary greatly by region, culture, class and tradition. But Buddhism puts an emphasis on encountering death that is answering a call in the West for a more spiritual approach to palliative care, hospice service and chaplaincy programs. “In Buddhism, there are a lot of texts and sutras that emphasize death and dying,” said Dr. Tuck Wai Chan, a physician in Singapore who has worked to bring Buddhist ideas about the end of life (EoL) into hospitals. “In certain traditions, the whole purpose of Buddhist practice is about death and dying. ... We know death well.” In the past decade and more, a Buddhist EoL movement has sprung up in Western

Europe, Australia, New Zealand and the U.S., testifying to a need for spiritual accompaniment at the EoL that is felt not only by an aging generation of Buddhist converts and immigrants but to those who only know that a secular, clinical approach is not enough. <https://bit.ly/2lwKb3O>

Specialist Publications

'The image of the children's hospice. The need for a permanent crisis communication' (p.8), in *Me.dok: média-történet-kommunikáció*.

'Elephant in the room – Family members' perspectives on advance care planning' (p.6), in *Scandinavian Journal of Primary Health Care*.

Specialist Publications

End-of-life care terminology: A scoping review

ADVANCES IN NURSING SCIENCE | Online – 9 November 2020 – The authors present an overview of terms found in publications associated with end-of-life care (EoLC) management that can impact decision-making by patients, healthcare providers, and researchers. Connotative terminology and syntax can influence the decision-making approach and process. The authors examined 49 publications for positive, negative, and neutral connotations. They consistently found negative terminology in the publications. To advance the development of nursing knowledge regarding EoLC, researchers should be aware of their biases of terminology and syntax use. The authors propose modifications to language used in EoLC planning models and literature can improve care congruency. **Abstract:** <https://bit.ly/38zPWsy>

Advancing palliative care in patients with chronic kidney disease: From ideas to practice

AMERICAN JOURNAL OF KIDNEY DISEASES | Online – 8 November 2020 – During the last 15 years, an engaged community of kidney care professionals, patients and researchers [in British Columbia, Canada] has embarked on a series of activities to adopt an integrated palliative approach to routine care in patients with chronic kidney disease (CKD)... Although the provincial renal network operates in a publicly funded healthcare system, where coordination across multiple healthcare organizations may be readily facilitated, the authors believe many activities described in this report are broadly applicable to many other settings, including single health maintenance organizations or for profit systems. Key activities include coordination of regular meetings and ongoing education of champions in the kidney care community, enabling access to supportive tools and resources, and embracing quality improvement principles. Continued engagement with key stakeholders throughout is critical. Whilst there is a recognized need to move ideas into practice, it is important to develop purposeful plans to ensure sustainability and true integration of palliative care practices into the care of patients living with CKD. **Full text (click on pdf icon):** <https://bit.ly/36yoYyL>

Noted in Media Watch 9 November 2020 (#691, p.3):

- *ADVANCES IN CHRONIC KIDNEY DISEASE*, 2020;27(4):350-355. '**Palliative care in nephrology: The work and the workforce.**' Kidney palliative care (PC), a growing subspecialty of clinical practice, education, and research in nephrology, is an essential aspect of care for patients across the continuum of advanced kidney disease (AKD) who have high symptom burden, multidimensional communication needs and limited life-expectancy. Training in kidney PC can occur in a variety of ways, from didactic curricula and clinical experiences embedded in nephrology fellowship training to the pursuit of additional dedicated fellowship training in PC. This article discusses opportunities and challenges in building a skilled workforce that will address the palliative needs of patients living with AKD. **Full text:** <https://bit.ly/3kPTv0N>

N.B. Additional articles on PC for people living with kidney disease noted in Media Watch 23 March 2020 (#658, p.5).

Introducing cross-cultural education in palliative care: Focus groups with experts on practical strategies

BMC PALLIATIVE CARE | Online – 10 November 2020 – This study corroborates a need for courses on cross-cultural issues for professionals who are involved in end-of-life (EoL) care. The focus groups stressed the importance of integrating such content into existing training offerings and ensuring that basic knowledge is acquired during undergraduate training, even before professionals decide to specialize in EoL related disciplines. In postgraduate and continuing education, joint learning among different professions is promoted. Two trends emerge related to course content: the acquisition of cultural expertise and tools for professionals to deal with complex situations on their own, and the importance of clinicians' reflecting and learning how to collaborate with other professionals in complex situations. These trends evoke recent debates in the literature: the quest for expertise and tools is related to traditional mainstream work on cultural competence, and reflection and collaboration are central to more recent research that promotes cultural sensitivity and humility in clinicians. **Full text:** <https://bit.ly/2lgsk1t>

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Noted in Media Watch 24 February 2020 (#654, p.8):

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 20 February 2020 – ‘**Cross-cultural experiences of hospice and palliative care services: A thematic analysis.**’ This study reviews the literature on the experiences of patients from non-Western and minority cultural backgrounds in hospice and palliative care (PC) services to inform clinical practice by Western providers. The key themes identified include: communication and flow of information, perceptions of hospice and PC, and compatibility with cultural beliefs. This review demonstrates similar themes across many non-Western and minority cultures interacting with hospice and PC services. These findings emphasize the importance of a cross-cultural approach in a PC and hospice setting. **Abstract (w. list of references):** <http://bit.ly/38WjLAE>

Tools for guiding interventions to address patient-perceived multidimensional unmet healthcare needs in palliative care: Systematic literature review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 11 November 2020 – The unmet needs of patients with advanced disease are indicative of the patient centredness of healthcare. By tracking unmet needs in clinical practice, palliative interventions are aligned with patient priorities, and clinicians receive support in intervention delivery decisions for patients with overlapping, complex needs. The majority of the 17 tools identified assessed unmet healthcare needs and had been validated. However, most did not link directly to clinical intervention, nor did they facilitate interaction between clinicians and patients to ensure a patient-reported view of unmet needs. Half of the tools reviewed covered ≤ 3 dimensions of palliative care. Of the 17 tools evaluated, 4 were compared in depth, but all were determined to be insufficient for the specific clinical applications sought in this research. **Abstract:** <https://bit.ly/32U1IKP>

Gaps in hospice and palliative care research: A scoping review of the North American literature

JOURNAL OF AGING RESEARCH | Online – 5 November 2020 – The demand for hospice and palliative care (PC) is growing as a result of the increase of an aging population, which is most prominent in North America. Despite the importance of the topic and an increase in hospice and PC utilization, there still are gaps in research and evidence within the field. Aim. To determine what gaps currently exist in hospice and palliative/end-of-life care research within the context of a North American setting to ensure that future directions are grounded in appropriate evidence. Major themes were identified through thematic context analysis: 1) Clinical; 2) System access to care; 3) Research methodology; and, 4) Caregiving related research gaps. Findings include strategies for engaging stakeholder organizations and funding agencies, implications for other stakeholder groups such as clinicians and researchers, and highlight implications for policy (e.g., national framework discussion) and practice (e.g., healthcare provider education and training and public awareness). **Full text:** <https://bit.ly/2lnDL7a>

Noted in Media Watch 10 February 2020 (#652, p.6):

- *BMC PALLIATIVE CARE* | Online – 3 February 2020 – ‘**International palliative care research priorities: A systematic review.**’ The authors call attention to the need for more end users in research priority setting exercises. Researchers and funding bodies should develop new strategies to ensure meaningful participation of palliative care (PC) patients and families, building in structures and processes to account for the vulnerability often present within this population. Findings provide an initial blueprint for PC research funders and policymakers to contribute to the future research agenda for PC from a patient and healthcare professional perspective. Given that funding resources are limited the importance of collaboration and international approaches to PC is growing... **Full text:** <http://bit.ly/37VsJxS>
- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 5 February 2020 – ‘**Economics of palliative care for cancer: Interpreting current evidence, mapping future priorities for research.**’ Early research studies on the economics of palliative care (PC) have reported a general pattern of cost savings during inpatient hospital admissions and the end-of-life phase. Recent research has demonstrated more complex dynamics, but expanding PC capacity to meet clinical guidelines and population health needs seems to save costs. Quantifying these cost savings requires additional research, because there is significant variance in estimates of the effects of treatment on costs, depending on the timing of intervention, the primary diagnosis, and the overall illness burden. **Abstract:** <http://bit.ly/3beeGW5>

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Noted in Media Watch 27 January 2020 (#650, p.12):

- *PALLIATIVE MEDICINE* | Online – 23 January 2020 – ‘Do journals contribute to the international publication of research in their field? A bibliometric analysis of palliative care journal data.’ Research impacts on health service provision and patient benefit. Journals play an important dissemination role, but there may be geographical bias, potentially affecting access to evidence. The authors sought to understand if there is a relationship between the continent of journals and that of contributing authors. North American authors are more present in North American journals and European authors in European journals. This polarised approach, if replicated across readerships, may lead to research waste, duplication and be sub-optimal for healthcare development. **Abstract (w. list of references):** <http://bit.ly/3aCr815>

“Advance” care planning re-envisioned

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 9 November 2020 – As it is, many of us have a hard time planning ahead for things far less complicated than advance care planning (ACP). Yet, we have become obsessed with this concept of “advance care planning” where we ask patients to make decisions in advance about the care or treatment they would or would not want IF they receive a diagnosis of a serious or life-limiting illness, rather than creating a culture of care planning that allows for agility, responsiveness, flexibility, and room for changing needs, views, or goals. It is time to refocus our approach of asking patients for an ACP document, which can only be hypothetical. We should replace the concept of ACP with an approach that emphasizes adaptive care planning in which treatment decisions in response to serious illness, changing diagnosis, prognosis, or personal circumstances are made when most relevant. Care planning that is flexible, longitudinal, and adaptive, that allows us to walk alongside our patients, supporting them step by step instead of expecting them to follow a document completed years earlier embodies care planning re-envisioned. **Full text:** <https://bit.ly/3p5TV5Q>

Elephant in the room – Family members’ perspectives on advance care planning

SCANDINAVIAN JOURNAL OF PRIMARY HEALTH CARE | Online – 11 November 2020 – In this Swedish study, family members’ experiences of advance care planning (ACP) in a nursing home context involved five themes: 1) Elephant in the room, comprising end-of-life issues being difficult to talk about; 2) Also silent understanding, e.g. patient’s preferences explicitly communicated, but also implicitly conveyed. (In some cases family members had a sense of the patient’s wishes although preferences had not been communicated openly); 3) Significance of small details, e.g. family members perceive everyday details as symbols of staff commitment; 4) Invisible physician, supporting nurse, e.g. nurse being a gatekeeper, providing a first line assessment in the physician’s absence; and, 5) Feeling of guilt, e.g. family members wish to participate in decisions regarding direction of care and treatment limits, and need guidance in the decisions. This study stresses the significance of staff involving the patient and family members in the ACP process in nursing homes, thereby adapting the care in line with patient’s wishes, and for the patient to share these preferences with family members. Education in communication related to the subject may be important to shape ACP. **Full text:** <https://bit.ly/2UhXyYn>

Noted in Media Watch 3 August 2020 (#677, p.9):

- *HEALTHCARE*, 2020;8(3):E218. ‘Advance care planning vs. advance serious illness preparations and planning.’ Much of the current advance care planning/advance directives movement has people (not patients) doing end of life planning/medical decision-making under conditions of certainty, devoid of context, and without support of clinical input. The way forward is to better prepare people for future serious illness decision-making, so they (or their surrogates) can better articulate their authentic values and informed treatment preferences in the context of “in the moment” shared medical decision-making with doctors and to help seriously ill patients with capacity to better plan their future medical care with their treating clinicians on documents recognized by the healthcare system. **Full text:** <https://bit.ly/30GUkAc>



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

COVID-19, moral conflict, distress, and dying alone

JOURNAL OF BIOETHICAL INQUIRY | Online – 9 November 2020 – COVID-19 has truly affected most of the world over the past many months, perhaps more than any other event in recent history. In the wake of this pandemic are patients, family members, and various types of care providers, all of whom share different levels of moral distress. Moral conflict occurs in disputes when individuals or groups have differences over, or are unable to translate to each other, deeply held beliefs, knowledge, and values. Such conflicts can seriously affect healthcare providers and cause distress during disastrous situations such as pandemics when medical and human resources are stretched to the point of exhaustion. In the current pandemic, most hospitals and healthcare institutions in the U.S. have not allowed visitors to come to the hospitals to see their family or loved ones, even when the patient is dying. The moral conflict and moral distress (being constrained from doing what you think is right) among care providers when they see their patients dying alone can be unbearable and lead to ongoing grief and sadness. The authors of this article explore the concepts of moral distress and

conflict among hospital staff and how a system-wide provider wellness programme can make a difference in healing and health. **Full text:** <https://bit.ly/2GMPNqf>

What matters? Palliative care, ethics, and the COVID-19 pandemic

JOURNAL OF BIOETHICAL INQUIRY | Online – 9 November 2020 – As is often the case in clinical ethics, the discourse in COVID-19 has focused primarily on difficult and controversial decision-making junctures such as how to decide who gets access to intensive care resources if demand outstrips supply. However, the lived experience of COVID-19 raises less controversial but arguably more profound moral questions around what it means to look after each other through the course of the pandemic and how this translates in care for the dying. This article explores the interface between the pandemic, ethics, and the role of palliative care (PC). The authors argue that the ethical discourse should be broader, and that the principles that underly the discipline of PC provide a solid ethical foundation for the care of all patients through the coronavirus pandemic. **Full text:** <https://bit.ly/3ndATbQ>

Noted in Media Watch 9 September 2019 (#630, p.10):

- *MORTALITY* | Online – 3 September 2019 – ‘**Moral ambiguity in media reports of dying alone.**’ The authors describe a media analysis of dying alone... They revisited a previous media analysis to examine whether news reporting of dying alone has changed. They focussed on a single case study to explore how an account of a lone death unfolded during the days following its discovery. The authors found dying alone remains a threat to individual and collective moral reputations. However, they also identified reports in which dying alone was presented as acceptable in some circumstances, and as congruent with aspects of a good death. The authors suggest that dying alone can be made good through media reporting, reflecting the individual choice and autonomy associated with a good death. **Abstract:** <http://bit.ly/2ksqSNq>

Noted in Media Watch 6 July 2020 (#673, p.8):

- *INTENSIVE CARE MEDICINE* | Online – 2 June 2020 – ‘**Alone, the hardest part.**’ The added value of family caregivers in the context of critical illness should not be overlooked amidst the COVID-19 pandemic. The authors urge clinicians to think differently ... and consider a decision-making framework that minimizes infection risk, honors patient/family relationships, upholds culturally important rituals of dying, and mitigates potential psychological harm precipitated by the trauma of family separation. With careful screening, education, pragmatic psychosocially oriented facilitation and teamwork, we can accommodate the very real needs of patients to not be alone, for families to fulfill their sense of responsibility and duty, and for staff to uphold the tenets of family-centered care. **Full text:** <https://bit.ly/2ZtQj1J>



Updated 11.12.2020

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 pp.11-12.

Lack of exposure to palliative care training for Black residents: A study of [U.S. medical] schools with highest and lowest percentages of Black enrollment

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 13 November 2020 – The palliative medicine workforce [in the U.S.] lacks racial diversity with <5% of specialty hospice and palliative medicine (HPM) fellows identifying as Black. Little is known about Black trainees' exposure to palliative care (PC) during their medical education. The authors of this study evaluated 24 medical schools in pre-determined categories: historically Black colleges and universities, and non-underrepresented minority-serving institutions with the highest and lowest percentage of Black medical students. Training opportunities were determined based on the presence of a course, clerkship or rotation in the medical school and residency curricula, a specialty HPM fellowship program, and specialty PC consult service at affiliated teaching hospitals. None of the four historically Black colleges and universities (HBCUs) with a medical school offered a PC course or clerkship, rotation during residency, or specialty HPM fellowship program. Three of four HBCUs were affiliated with a hospital that had a PC consult service. Institutions with the highest Black enrollment were less likely to offer PC rotations during internal medicine or family medicine residency training than those with the lowest Black enrollment. Residents at schools with the highest Black medical student enrollment lack access to PC training opportunities. **Abstract (w. list of references):** <https://bit.ly/32LUqZh>

The image of the children's hospice. The need for a permanent crisis communication

ME.DOK: MÉDIA-TÖRTÉNET-KOMMUNIKÁCIÓ, 2020;15(3): 49-65. The holistic hospice-palliative care of dying persons turned into a generally accepted approach in Hungary only after the 1989 regime change. Specific children's hospices were established in 2011. These organizations had to face the fact that their everyday work is even more difficult than the hospices for adults because of the highly sensitive, often rejected and neglected field they work in. From a marketing communication and public relations standpoint ... children's hospices are in a permanent crisis situation and as a part of it they need to follow a well-designed crisis communication strategy on a daily basis. The authors discuss the main social reasons of this situation – illustrated by the example of the only functioning children's hospice institution in Hungary, the Tabitha House [in Törökbálint (nearby Budapest)] – namely the taboo of death, the misconceptions around the term hospice, the general mistrust toward social organizations, and the low level of social participation. The authors ... analyse these phenomena and to present some online communication methods by the example of the Tabitha House, which can facilitate the process of the strategic planning and decision-making of the children's hospices and the organizations working with a socially sensitive issue. **Abstract:** <https://bit.ly/2GJvWZ0>



N.B. Hungarian language article. Tabitha House website: <https://bit.ly/3ldrlqg>

Noted in Media Watch 28 May 2018 (#565, p.9);

- *EUROPEAN JOURNAL OF PEDIATRICS* | Online – 21 May 2018 – ‘**The timing and circumstances of the implementation of pediatric palliative care in Hungarian pediatric oncology.**’ There is an international consensus that palliative care (PC) should commence at the diagnosis of a pediatric malignant disease regardless of illness outcome. Despite the continuous improvement of pediatric PC barriers to the early implementation of PC in pediatric oncology involve resource-based and attitudinal factors. In Hungary, where pediatric oncologists are sole decision-makers, early implementation of PC is rare. There is a preference among physicians for working within a team, while also asserting that presence of team members may decrease the level of intimacy. **Abstract (inc. list of references):** <https://bit.ly/2U9QZGY>



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Rapid implementation of eMOLST order completion and electronic registry to facilitate advance care planning: MOLST documentation using telehealth in the COVID-19

NEJM CATALYST | Online – 3 November 2020 – During the COVID-19 pandemic in New York City there was a need to innovate to meet patient needs, including recognizing the value of medical orders as an advance care planning (ACP) tool. Accelerated adoption of eMOLST (Electronic Medical Orders for Life Sustaining Treatment), an electronic order completion and statewide public health registry, provided an opportunity to complete both general ACP and MOLST during telehealth encounters. Over three days, the authors enrolled and trained 154 members of the Mount Sinai Health System Department of Geriatrics & Palliative Medicine, including primary care and specialty inpatient and outpatient practices, in the use of eMOLST, utilizing a connection to eMOLST within the department's electronic health record. In the initial month after launch, during the height of the COVID-19 outbreak, 183 new patients were entered into eMOLST from various settings, using telehealth encounters. The authors describe key factors that facilitated the rapid implementation and benefits of the eMOLST program. **Full text:** <https://bit.ly/3n3fjXB>

Noted in Media Watch 21 January 2020 (#598, p.9):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 14 January 2019 – ‘**Electronic medical orders for life-sustaining treatment in New York State: Length of stay, direct costs in an ICU setting.**’ Electronic Medical Orders for Life-Sustaining Treatment (eMOLST) is a standardized documentation process used in to convey patients' wishes regarding cardiopulmonary resuscitation and other life-sustaining treatments. No study to date has looked at the effect of eMOLST as an advance care planning tool on ICU and hospital costs using estimates of direct costs. A retrospective chart review was conducted... Completing an eMOLST form did not have any effect on reducing total direct cost, ICU cost, total length of hospital stay, and total hours spent in the ICU. **Abstract (w. references):** <https://bit.ly/3kinP3b>

Palliative care in the U.S.

Engaging primary care physicians to refer patients to home-based palliative is challenging and complicated

PALLIATIVE MEDICINE REPORTS | Online – 5 November 2020 – This study holds several important implications for practice and new approaches to engaging primary care physicians (PCPs) in home-based palliative care (PC), obtaining buy-in, and generating patient referrals. Findings suggest the crucial role that factors such as physician PC knowledge, time constraints, practice structure, and collaborative care styles and preferences serve to successfully engage PCPs in new models of care such as HBPC. It also brings into question the amount of information that PCPs can reasonably retain over a one-hour conversation or lunch meeting, which bears resemblance to in-office visits from pharmaceutical representatives. Several areas identified in this research may be amenable to change, however, it is likely that the largest barrier is lack of PC health literacy as it relates to the widespread clinician-held myth of equating PC with hospice. Correcting misconceptions such as this one may help PCPs begin to become more willing to try HBPC for some patients, thereby better meeting the multifaceted health and social needs of complex patients and reducing burden on themselves and their medical practice. **Full text:** <https://bit.ly/38gqxJy>

Death and grieving for family caregivers of loved ones with life-limiting illnesses in the era of COVID-19: Considerations for case managers

PROFESSIONAL CASE MANAGEMENT | Online – 10 November 2020 – Family caregivers of a loved one with a life-limiting or terminal illness are often overwhelmed by, and underprepared for, their responsibilities. They often need help from family members and friends to provide comprehensive care. When death occurs, funerals and other death-related rituals bring family and communities together to honor the life and mourn the death of a loved one and provide needed support to family and caregivers. These collective rituals are often deeply rooted in culturally-bound values and can facilitate grief and help make sense about loss. Rituals act as bridge-building activities that allow people to organize and appraise emotions, information, and actions after a loss. With the emergence of the coronavirus disease-2019 (COVID-19) pandemic and

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the recommended restrictions to reduce infection and transmission, family members and caregivers are often faced with weighing options for honored rituals to help them grieve. Grieving during the pandemic has become disorganized. The purpose of this article is to provide case managers and other clinical staff with recommendations on guiding caregivers/families through safety precautions when a loved one dies either because of a life-limiting illness or from COVID-19 during the pandemic using guidelines from the Centers for Disease Control & Prevention. The authors also present information about complicated grief and ways to support coping with death and suggest safe alternatives to traditional death-related rituals and funerals in a COVID-19 era. **Abstract:** <https://bit.ly/3ksAil8>

**International transfer and translation of an end-of-life care intervention:
The case of the Liverpool Care Pathway for the dying patient**

WELLCOME OPEN RESEARCH | Online – 27 October 2020 – The authors explore how and why the Liverpool Care Pathway (LCP) for the dying patient was transferred to 20 countries beyond the U.K., and with what consequences for policy and practice. This article synthesises findings from 95 publications contained in a historical narrative literature review on the implementation of the LCP outside the U.K., alongside data from 18 qualitative interviews with 19 key actors involved with the LCP in 14 countries. The authors ... explore the timelines and patterns of development and implementation in the specific countries, to consider what forms of research and evaluation about the LCP were undertaken to establish its effectiveness, and to summarise the resulting findings and their consequences. They use the interviews to gain insights into the elements, processes and dynamics that shaped the transfer and translation of the LCP from one location to another, across national boundaries. Using six questions from the policy transfer literature the authors then explain who were the key actors involved; what was transferred; from where lessons were drawn; the different degrees of transfer that took place; what restricted or facilitated transfer; and how transfer was related to “success” or “failure.” The authors conclude that the spread of the LCP took place mostly in prosperous countries, and was sustained over around 15 years. It took in differing geographies and cultures, and a variety of linguistic, policy and practice contexts. If it did not succeed in a wider transformational goal, it appears to have been well received and perceived as beneficial in many contexts, largely avoiding accusations of misuse and harm that had occurred in the U.K., and in some cases fostering a sustained international collaboration and ongoing use of local variants, even after withdrawal in its country of origin in 2014. **Full text:** <https://bit.ly/3lbEWOz>



N.B. At the time it was accessed on the Wellcome Open Research website, this article was subject to peer review. Additional articles on the LCP noted in Media Watch 10 February 2020 (#652, p.13) and 13 July 2020 (#674, p.7).

Noted in Media Watch 27 January 2020 (#650, p.12):

- *PALLIATIVE MEDICINE* | Online – 23 January 2020 – ‘**Do journals contribute to the international publication of research in their field? A bibliometric analysis of palliative care journal data.**’ Research impacts on health service provision and patient benefit. Journals play an important dissemination role, but there may be geographical bias, potentially affecting access to evidence. The authors sought to understand if there is a relationship between the continent of journals and that of contributing authors. North American authors are more present in North American journals and European authors in European journals. This polarised approach, if replicated across readerships, may lead to research waste, duplication and be sub-optimal for healthcare development. **Abstract (w. list of references):** <http://bit.ly/3aCr8i5>

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Cont.

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