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

While need to improve palliative care in long-term care settings is recognised globally, most initiatives are* ad hoc *bespoke programmes that fail to recognise clinical setting characteristics or measurable outcomes.

'Palliative and end-of-life educational interventions for staff working in long-term care facilities: An integrative review of the literature' (p.8), *International Journal of Older People Nursing.*

Canada

Caregiving can last for decades, new research shows

ALBERTA | *Folio* (University of Alberta) – 14 September 2020 – To most people, "caregiving" means looking after ailing relatives in their final years. But the reality is much different, with the actual workload lasting up to 30 years for some, according to University of Alberta research.[1] The study, the first of its kind to gauge caregiving across a person's lifetime, debunks the myth that looking after an ailing loved one is a short, one-off experience. Lengthy caregiving can take a high personal toll, including chronic stress, loneliness, poor health, disrupted careers or pensions and crumbled relationships. The study identified five different lifetime patterns of caregiving. Some start early, others in mid-life or later, and they vary in intensity. A "compressed generational" care trajectory was the most common pattern, with over half of caregivers starting their responsibilities at age 63 on average, with the shortest duration of four years, typically looking after a spouse or parent. Just 13% of them had a second episode of caregiving with almost no overlap between care episodes. The next most frequent pattern, known as the broad generational care trajectory, started when caregivers were in their early 50s, involved more than one care episode – typically caring for parents, partners or sometimes friends – and lasted for a total of 14 years. https://bit.ly/3c2ymwV

Specialist Publications

'Perceptions of palliative care in a South Asian community [in Ontario, Canada]: Findings from an observational study' (p.4), in *BMC Palliative Care.*

'Framework on palliative care in Canada: Do we have a broad enough lens?' (p.7), in *Canadian Family Physician.*

'Workforce planning for community-based palliative care specialist teams using operations research' (p.10), in *Journal of Pain & Symptom Management.*

'Palliative care provision at a tertiary cancer center during a global pandemic' (p.12), in *Supportive Care In Cancer.*

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1. 'Trajectories of family care over the lifecourse: Evidence from Canada,' *Ageing & Society*, published online 8 January 2020. **Full text:** https://bit.ly/3hwT09K

U.S.A.

Death in the time of COVID-19: Hospice care is tough to get right now

CALIFORNIA | *The Orange Country Register* – 13 September 2020 – Difficult as the past six months have been on the living, and the terrible cost paid by those who have died, there's another category of people for whom the Coronavirus pandemic has shown little mercy – those seeking hospice care. Whether they're in the final stages of a long-term illness, or they've been diagnosed with terminal cancer, or they're suddenly stricken with COVID-19, dying people are facing a variety of pandemic-related hurdles to get a service designed to comfort the afflicted and ease the burden for their family members. That service includes helping people handle fear. Even when their health is in decline, many people with serious illnesses remain afraid to visit a doctor or go to a hospital because of the specter of Coronavirus. As a result, they don't get the assistance that could ease the final stage of life. Some who are terminally ill won't seek hospice care because they fear a more precipitous death from COVID-19, providers say. Others are referred by doctors or discharged from hospitals at a point when their disease is well advanced, delays that come because the patient has avoided getting medical evaluation; again, out of fear of Coronavirus exposure. Eligibility for end-of-life care is restricted to people deemed to be in the last six months of life. But hospice care sometimes can prolong someone's life, and some people end up being taken off hospice because their health has improved. But that scenario is less likely when the hospice process gets started late. Also, the same fear of Coronavirus that's prompting people to put off hospice care is prompting delays in getting general medical care that might improve a patient's health. https://bit.ly/3hqLPja

Specialist Publications

'Conflicting orders in Physician Orders for Life-Sustaining Treatment forms' (p.9), in *Journal of the American Geriatrics Society.*

'Models of palliative care delivery for individuals with cystic fibrosis: Cystic Fibrosis Foundation evidence-informed consensus guidelines' (p.11), in *Journal of Palliative Medicine.*

'Recommendations for palliative and hospice care in the [U.S.] National Comprehensive Cancer Network guidelines for treatment of cancer' (p.11), in *The Oncologist.*

Noted in Media Watch 7 September 2020 (#682, p.10):

- *MORTALITY* | Online – 30 August 2020 – **'Addressing fear of death and dying: Traditional and innovative interventions.'** The fear of death and dying is a multifaceted and prevalent source of human distress that can cause significant psychological and existential distress, especially at the end of life (EoL). Analysing current therapeutic approaches to this issue to identify promising modalities and knowledge gaps could improve EoL experiences and reduce human suffering. The authors analyse recent literature to explore treatments for thanatophobia. Effective intervention strategies for fear of death and dying do exist, but all have practical and therapeutic limitations. Psychotherapy appears to be an effective tool at reducing death anxiety. **Abstract:** https://bit.ly/3gHR3qr

International

Children's hospice

Delivering human connection through meaningful architectural design

AUSTRALIA (Queensland) | *Hospital & Healthcare* – 17 September 2020 – The under investment in palliative care (PC) in Australia is a sad reality that is again in the spotlight, but should not be ignored. A report commissioned by Palliative Care Australia calls for an overhaul of the PC system in Australia and an additional annual investment of $365 million to bring the system up to speed in a post COVID-19 world.[1] The

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National Palliative Strategy 2018 identifies that PC is not equally available to all Australians.[2] In 2012 the federal government's study into PC found that 3,700 children in Queensland were living with life-limiting conditions.[3] At that time there were only two children's hospices in Australia: one in Victoria and another in New South Wales. This led to the development of Hummingbird House Queensland. The state-of-the-art children's hospice, finished in 2016, is the only one of its kind in Queensland and took the total of children's-only hospice facilities in Australia to three. Hummingbird House gave us important insights into how architectural design can contribute to end-of-life care for all people – particularly for children and teenagers and the impact on their families. It highlighted the tight bonds that exist between design, aesthetics and emotions. The design solution for Hummingbird House was a direct result of an empathic and human-centred design process involving an extensive briefing and engagement process that included workshopping and research. https://bit.ly/3hFY9MH

1. 'Investing to Save – The economics of increased investment in palliative care in Australia,' Palliative Care Australia, May 2020. [Noted in Media Watch 1 June 2020 2020 (#668, p.5): **Download/view at:** https://bit.ly/3d8DFL2

2. 'The National Palliative Care Strategy 2018,' Australia Government, 2018. **Download/view at:** https://bit.ly/2ZHAK7t

3. 'Palliative Care Services in Australia,' Australian Institute of Health & Welfare. **Download/view updated report at**: http://bit.ly/2QekeFX

N.B. Selected articles on the relationship between the architecture of healthcare facilities and the quality of end-of-life care noted in Media Watch 18 May 2020 (#666, p.7).

Close to 50% increase in end-of-life care hospitalisations [in Australia]

AUSTRALIA | Royal Australian College of General Practitioners – 15 September 2020 – A new Australian Institute of Health & Welfare (AIHW) found almost one in 140 (0.7%) of all hospitalisations (11.3 million) in 2017-2018 were palliative care (PC) related. That is a total of 79,932, 57% of which were for PC and 43% for other end-of-life care (EoLC). By using time series data from the National Hospital Morbidity Database to compare 2013-2014 to 2017-2018, the analysis has been able to for the first time separate PC hospitalisations and other EoLC hospitalisations, the latter being where care was not necessarily delivered by a PC specialist. Over the three-year period, there was a 16.9% increase in PC hospitalisations from about 39,000 to almost 45,600, and a 48.2% increase in other EoLC hospitalisations from about 23,200 to almost 34,400. A 16% increase in hospitalisations was noted for all reasons over the same period. https://bit.ly/3c5X3Zl

N.B. Download/view AIHW report at: https://bit.ly/3c5X3Zl

Half the population [in Ireland] believe discussing palliative care is more important because of COVID-19

IRELAND | All Ireland Institute of Hospice & Palliative Care (Dublin) – 13 September 2020 – Half the population think COVID-19 has increased the importance of discussing palliative care (PC). The finding is from a new survey of perceptions of PC commissioned by the Institute. The survey of people in the Republic of Ireland, carried out in July 2020, also found that 4 in 5 people would like to be supported to discuss and write down their wishes and preferences for care at the end of life (EoL). The findings also demonstrate that misconceptions exist about PC. The survey found that 1 in 3 people think PC is a last resort, whereas PC may be appropriate for a number of years, not just for weeks and days at the EoL. https://bit.ly/3isW9IG

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Noted in Media Watch 10 February 2020 (#652, p.7):

- *HRB OPEN RESEARCH* | Online – 3 December 2019 – **'Population-based palliative care planning in Ireland: How many people will live and die with serious illness to 2046?'** The number of people in Ireland dying from a disease associated with palliative care (PC) need is estimated to increase 68% between 2016 and 2046 if levels of need stay constant. Under assumptions of changing need, increases are estimated in the range 78-84% depending on projection method employed. The equivalent estimates for England & Wales between 2015 and 2040 are 25% with constant needs and up to 47% with changing needs.[1] The number of people living with a disease associated with PC need outnumber those in the last year of life with a relevant diagnosis. **Full text:** http://bit.ly/2OzrhJJ

    1. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services,' *BMC Medicine*, published online 18 May 2017. [Noted in Media Watch 22 May 2017 (#513, p.11)] **Full text:** http://bit.ly/2IHcYCi

Media Watch 26 August 2019 (#628, p.4):

- IRELAND | Health Research Board (Dublin) – 21 August 2019 – **'Out-of-hours specialist and generalist palliative care service provision: An evidence review.'** Ireland's current position is typical among high-income countries with well-established services. That is, the importance of integrated, 24-hour care for people with serious and complex medical illness is widely acknowledged, but details on how to organise, provide, and evaluate out-of-hours services are scant. Barriers included insufficient resources, inadequate knowledge among practitioners and patients, a lack of guidance for non-specialists, inadequate communication between out-of-hours services and other parts of the healthcare system, and insufficient knowledge or confidence among unpaid caregivers. **Download/view at:** http://bit.ly/2L4gPYh

Specialist Publications

Why should everybody learn Last Aid to provide end-of-life care?

ARCHIVES OF COMMUNITY MEDICINE & PUBLIC HEALTH, 2020;6(2):198-199. Last Aid (LA) courses have been created to inform the public about palliative care (PC) and to encourage an open public discussion about death and dying. They inform people about what they can do to relieve suffering and provides information where citizens can get help from professionals. LA courses have been piloted in Germany, Norway and Denmark. A recent pilot study has shown that special LA courses for children and teenagers are very much appreciated by the participants and that the majority of children and teenagers want to talk about death and dying. LA should therefore be a part of life-long learning in the same way this is true for first aid. LA training should thus start in school. At present sixteen countries participate in the International LA working group. More than 26,000 citizens have been taught LA and more than 2,000 LA course instructors have been educated. **Full text:** https://bit.ly/3ksMUZD

Publishing Matters

'Predatory journals in the age of COVID-19' (p.12), in *Himmelfarb Library News*.

Perceptions of palliative care in a South Asian community [in Ontario, Canada]: Findings from an observational study

BMC PALLIATIVE CARE | Online – 14 September 2020 – Recent research in Ontario, Canada, has demonstrated that immigrants originating from South Asia have the highest risk of aggressive end-of-life (EoL) care, when compared to those born in other regions of the world. Further to these findings, the authors' study observed a significant lack of knowledge and awareness regarding palliative care (PC) among South Asian study participants. The lack of knowledge in patients regarding PC and EoL care was shown to be prevalent in close to 50% or more of the studied population in multiple sources, something observed in 70%

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of our South Asian patient population. The gap in knowledge regarding PC is likely to be at least a contributing factor resulting in the increased likelihood of aggressive EoLC in the South Asian population, a trend also noted in other racialized populations and immigrant communities. This disconcerting trend of lack of awareness regarding PC has remained alarmingly high for the past 15 years. It was telling that many of study participants wanted to avoid pain and suffering and associated PC with better quality of life and family supports. None of our participants explicitly voiced a desire for aggressive or futile interventions at EoL. All of these are treatment goals consistent with the key principles of PC, whose components include symptom management and monitoring, discussions about advance care planning and goals of care, and extra support for both the patient and family via an interdisciplinary team. **Full text:** https://bit.ly/2ZG1sNM

How effective is undergraduate palliative care teaching for medical students? A systematic literature review

BMJ OPEN | Online – 9 September 2020 – Most types of palliative care (PC) teaching interventions conducted with medical students improve knowledge. This provides useful information for medical schools when considering the teaching they currently provide, or aim to provide, in the future. The effect of undergraduate PC teaching on clinical practice has not been studied and warrants investigation. For all teaching approaches, constructive alignment and the communication of constructive alignment in educational studies should be considered to ensure adequate teaching impact. Further research into PC teaching should explicitly detail this alignment to allow for evaluation as to whether constructive alignment, not the teaching method, may be responsible for any effect of PC teaching interventions. Medical students can learn about PC using a variety of methods; there is no definitive "best" way to learn about PC. We have the responsibility to not just train medical students to pass exams, but to be safe and knowledgeable doctors. Given this, future research needs to assess the effect of teaching on clinical practice, including some analysis of patient-related outcomes, in order to discern the real-world impact of PC teaching interventions. **Full text:** https://bit.ly/2E1aVaH

How can existential or spiritual strengths be fostered in palliative care? An interpretative synthesis of recent literature

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 14 September 2020 – The 'Propeller' framework, a model of existential/spiritual strength approaches, can help professionals working in palliative care (PC), especially those not specialised in spiritual care, in a number of ways. First, it stimulates awareness that there are specific approaches that can lead to patient experiences of existential or spiritual strength, and that these ways are important from a distress-reducing perspective, and from a viewpoint of (final) human flourishing. This awareness can also be supported by the insight that the existential or spiritual is often found in everyday, simple things, and is mostly not situated in an otherworldly dimension out there, but in an essential dimension right here. Second, through awareness of the found approaches, care professionals can learn to align and coordinate their care more to find and foster existential or spiritual strengths. This can take the form of better facilitating what is already happening, of providing guidance to patients who are trying to find their way or of stimulating patients' awareness of another, possibly more positive, side. Third, the propeller model can offer

The existential dimension of palliative care: The mirror effect of death on life

OMEGA – JOURNAL OF DEATH & DYING | Online – 16 September 2020 – The World Health Organization has included the spiritual dimension in its definition of palliative care (PC) since 1990, but this dimension is frequently confused with notions of religion. Yet, the spiritual suffering experienced by PC patients is primarily a matter of existential suffering. The objective of this study was to examine the ways in which the existential dimension was manifested in the experiences of those present in a PC unit. The existential dimension appears to reside in the connections between individuals and the proximity of death appears to shed new light on the meaning of life. The mirror effect of death on life, could serve to encourage greater appreciation of the value of our connections with others, and the desire to take care of others, which offers new insight into forms of solidarity and social organisation. **Abstract b(w. list of references)**: https://bit.ly/3mpBkAx

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professionals a starting point to become aware of other ways to find and foster existential or spiritual strengths. The 5 strengths and 16 approaches identified are only a preliminary configuration, to which existing, non-scientific but pragmatic approaches, for instance, of experienced nurses in PC, can be added. With all the above applications, however, the framework must not be seen as a way to simply assess a patient's strengths. Professionals should be mindful of the finding that existential or spiritual strengths emerge out of and build on creative relationships between that individual and his or her environment. **Full text:** https://bit.ly/35CBkqM

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

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 July 2020 – **'The urgency of spiritual care: COVID-19 and the critical need for whole-person palliation.'** Although spiritual care has long been recognized as one of the domains of quality palliative care (PC), it is often not fully integrated into practice. All disciplines are ultimately responsible for ensuring spiritual care is prioritized to improve quality of life and the experience of patients and families facing spiritual emergencies amid the complex life-and-death scenarios inherent to COVID-19. Although the pandemic has revealed serious fault lines in many healthcare domains, it has also underscored the need to recommit to spiritual care as an essential component of whole-person PC. **Abstract (w. list of references):** https://bit.ly/2NVNxww

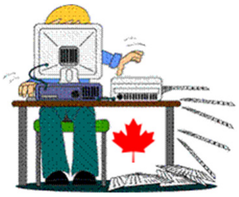
Noted in Media Watch 18 May 2020 (#666, p.15):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 11 May 2020 – **'Caring for the patient with cancer: Body and soul.'** Is oncology a spiritual practice? It is important, if not essential, to recognize how patients contextualize their illness. As a medical oncology fellow, the author has engaged in existential questions that patients dying from cancer often ask. What is the meaning of my illness? Why am I suffering? Recognizing illness as a spiritual event did not come from any classroom experience, but from experiential learning. The transcendent, spiritual nature of medicine is found in the crevices of daily practice. The spiritual nature of medical care begins when we acknowledge how much patients and healthcare professionals suffer. **Abstract (w. link to references):** https://bit.ly/2SVCmqz

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

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

N.B. Additional articles on spirituality noted in 20 January 2020 issue of Media Watch (#649, p.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

Framework on palliative care in Canada: Do we have a broad enough lens?

CANADIAN FAMILY PHYSICIAN, 2020;66(9):642-643. In December 2018, Health Canada released a report entitled the 'Framework on Palliative Care in Canada.'[1] This document was thoughtfully prepared, incorporated broad input, and clearly identified some important changes needed in our healthcare system. While we applaud the directions outlined in the report, we also believe it represents a substantial missed opportunity, as its recommendations for improved palliative care (PC) focus almost exclusively on the formal healthcare system. A framework offers a roadmap for where we want to go and thus needs to be clear regarding the direction. If Canadians are intent on improving our experiences in the last stage of life, then considerable future attention needs to focus on communities and social structures. Public health statistics remind us that approximately 90% of deaths in Canada are the result of progressive incurable illness and that in the last year of life, the average Canadian will spend less than 5% of his or her time in the treatment of the formal healthcare system. Many jurisdictions around the world have realized that the success of their formal healthcare systems for PC is contingent on partnering with communities to provide care during these years and "the other 95%" of time. In this sense, community involves all environmental elements contributing to the physical, emotional, social, and spiritual wellness and the overall quality of life of patients, families, and caregivers. In addition to the traditional healthcare system, community includes (but is not limited to) friends, the workplace, schools, neighbours, faith communities, and volunteer organizations advocating and providing assistance and practical support for those facing serious illness and death. **Full text:** https://bit.ly/2FHthhD

1. 'Framework on Palliative Care in Canada,' Health Canada, 2018. [Noted in Media Watch 10 December 2018 (#593, p.1)] **Download/view at:** http://bit.ly/2AVEghF

N.B. Download/view French language version of *Canadian Family Physician* article, 'Le cadre sur les soins palliatifs au Canada: Notre perspective est-elle assez large?' at: https://bit.ly/3c1fIWn

Ethical considerations in the use of artificial intelligence mortality predictions in the care of people with serious illness

HEALTH AFFAIRS | Online – 16 September 2020 – When health systems integrate mortality predictions into electronics health records at the point of care, generate risk-stratified lists of patients with a range of time-based prognoses, and use these analytics to prompt or even automatically order palliative care (PC) consults, they are responding to well-known deficiencies in the care of people with serious illness. Studies consistently show that patients and family caregivers may be unaware of prognosis; that physicians are often inaccurate or reluctant to share detailed prognostic information; and, that patients of certain socio-economics statuses or races may be less aware of their prognosis. People with serious illness are at risk of physical and psychological suffering at the end of life (EoL), in large part due to care that is out of alignment with their priorities. Artificial intelligence (AI) can identify these patients while there is still time to intervene. For patients who desire it, prognostic information should ideally help them make decisions about treatments, prepare for the future, and focus on their priorities. The use of automated AI algorithms by PC teams, health systems, or even payers to identify people approaching the EoL to prevent unwanted and non-beneficial care is an important goal. Because these people often incur high costs, reducing unwanted care can have the added benefit of lowering costs. Yet, despite AI's potential, there is a need to address at least three core ethical issues before implementation of AI in this unique context. **Full text:** https://bit.ly/3iBGGpP

Ethical issues

First, automated algorithms could cause subtle shifts in how shared decision-making plays out.

Second, algorithms to predict prognosis can exacerbate disparities for people with serious illness, since electronic health record data and AI algorithms are susceptible to significant biases.

Third, there is considerable risk at present if these algorithms are running in the background or used without patients' and families' awareness.

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Noted in Media Watch 2 March 2020 (#655, p.11):

- *THE LANCET*, 2020;395(10225):680-681. **'Power and perils of prediction in palliative care.'** Machine learning technologies can be useful in palliative care (PC), especially as clinicians and health systems seek to allocate and improve access to scarce PC resources. The potential of machine learning models in PC is their capacity to rapidly analyse data from various sources to predict who is likely to progress to unacceptable functional dependence or even die. Such predictions can signal who might need additional support, such as targeted communication or a PC consult. Appropriately timed introduction of PC services improves outcomes … and healthcare spending efficiency. Figuring out who should get specialty PC and when is one of the field's most pressing questions. **Full text:** http://bit.ly/2IgcUGV

Palliative and end-of-life educational interventions for staff working in long-term care facilities: An integrative review of the literature

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 12 September 2020 – The present review suggested considerable variability in educational interventions and noted a lack of globally standardised interventions to date. Only one study attempted an intervention across seven countries; the findings showed great variances across and within these countries. Implementation of their intervention was influenced by the programme itself and its delivery, how and what kind of people were involved in the programme and the implementing practice's context. Given that level of palliative care (PC) development and long-term care (LTC) facilities differ from one country to another and that diverse educational backgrounds and practice experience of staff members, this study highlighted that preparing and providing standardised programmes that meet unique educational goals and needs has remained a challenge. Also, the included studies were conducted in countries where PC is at an advance stage of integration and there is less evidence from countries with less integration. Therefore, it is important to question whether such standardisation is required and whether it is more helpful to consider "core" competencies along with specific competencies for different roles and responsibilities, rather than a one-size-fits-all approach. Educational intervention for LTC facilities staff needs to include more consideration of context, organisational culture and the user involvement throughout the process of education and research to enhance the quality of care in this complex setting. **Full text:** https://bit.ly/2ZAhJDL

Noted in Media Watch 10 February 2020 (#652, p.12):

- *PALLIATIVE MEDICINE* | Online – 3 February 2020 – **'Strategies for the implementation of palliative care education and organizational interventions in long-term care facilities: A scoping review.'** The findings of the review highlight that the feasibility of implementing palliative care interventions is largely dependent on the context and the extent to which delivery can be tailored to the individual needs of the facility, its staff and its residents. In addition, successfully implemented interventions were able to either improve or adapt to relatively poor existing conditions. These included poor communication between health professionals, long-term care facilities staff and families, high staff turnover and unsupportive management or a lack of leadership. **Full text:** http://bit.ly/385z3mc

Noted in Media Watch 25 November 2019 (#641, p.8):

- *BMC PALLIATIVE CARE* | Online – 19 November 2019 – **'Palliative care nurse specialists' reflections on a palliative care educational intervention in long-term care: An inductive content analysis.'** The overall impression of palliative care (PC) nurse specialists was that the implementation of a PC education intervention supports the building of a strong relationship between the hospice nurse specialists and facilities, facilitates improved communication between registered nurses (RNs) and residents and RNs and families and alerts RNs to be vigilant in assessing the PC needs of their residents. The more the PC nurse specialists interacted with long-term care registered nurses and healthcare assistants, the better the knowledge base for both sides. **Full text:** http://bit.ly/35ooKbr

Conflicting orders in Physician Orders for Life-Sustaining Treatment forms

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 16 September 2020 – Many older persons with chronic illness use Physician Orders for Life-Sustaining Treatment (POLST) to document portable medical orders for emergency care. However, some POLSTs contain combinations of orders that do not translate into a cohesive care plan (e.g., cardiopulmonary resuscitation without intensive care, or intensive care without antibiotics). This study characterizes the prevalence and predictors of POLSTs with conflicting orders. 3,123 POLST users with chronic life-limiting illness who died between 2010 and 2015 participated. Although most POLSTs are actionable by clinicians, 5% had conflicting orders for cardiac arrest and medical interventions, and 24% had one or more conflicts between orders for cardiac arrest, medical interventions, antibiotics, and artificial nutrition. These conflicting orders make implementation of POLST challenging for clinicians in acute care settings. **Abstract:** https://bit.ly/2RwF9pk

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

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

Shared decision-making with people with intellectual disabilities in the last phase of life: A scoping review

JOURNAL OF INTELLECTUAL DISABILITY RESEARCH | Online – 11 September 2020 – Although it is emphasised in the literature that people with intellectual disabilities (ID) should be involved in decision-making in the last phase of life, a uniform best practice about what this should look like is lacking. On the basis of the results of this review, the authors recommend developing an aid that specifically supports systematically taking preferences of people with ID in the last phase of life into account. As indicated in the literature, even if a person is not able to actually participate in the decision-making process, decisions can be aligned to the values and preferences of a person with ID. This can be achieved by involving the inner circle around the person with ID and by looking at the life history and earlier medical experiences of the person with ID. To make good decisions, professionals and relatives should be attentive to the expression and signals of needs and distress a person with ID is giving. A good relationship between relatives and professionals is essential to ensure good end-of-life care in the best interest of the person with ID. **Full text:** https://bit.ly/35CEPgO

Noted in Media Watch 10 August 2020 (#678, p.10):

- *BRITISH JOURNAL OF LEARNING DISABILITIES* | Online – 30 July 2020 – **'Disclosure and plan of care at end of life: Perspectives of people with intellectual disabilities and families in Ireland.'** This study has shown how people with intellectual disabilities (ID) and family members presume that receiving adequate information and engaging in an advanced care planning process gives people with ID some control over their future care. The practitioners could infer from these findings that end-of-life decision-making could take an inclusive approach, whereby the wishes and views of people with mid and moderate ID are respected and recorded in their clinical file, which will accompany them wherever they are transferred to. **Full text:** https://bit.ly/3kfMcjs

N.B. Selected articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in Media Watch 3 August 2020 (#677, p.10) and 8 June 2020 (pp.8-9).

Workforce planning for community-based palliative care specialist teams using operations research

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 14 September 2020 – The authors developed a population-need, workforce planning model for community-based palliative care (PC) specialist teams and to apply the model to forecast the staff needed to care for all patients with terminal illness, organ failure, and frailty over the next twenty years, with and without the expansion of primary PC. To meet the PC needs for persons dying across Nova Scotia, Canada, in 2019, the model generated an estimate of 70.8 nurses, 23.6 physicians and 11.9 social workers, a total of 106.3 staff. Thereby, the model indicated that a 64% increase in specialist PC staff was needed immediately, and a further 13.1% increase would be needed over the next 20 years. Trained primary PC providers currently meet 3.7% of need, and with their expansion are expected to meet 20.3% by 2038. Historical, current, and projected data can be used with operations research to forecast staffing levels for specialist PC teams under various scenarios. The forecast can be updated as new data emerges, applied to other populations, and used to test alternative delivery models. **Full text:** https://bit.ly/35BR0dN

Assessing the will to live: A scoping review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 12 September 2020 – The will to live (WTL) is an important factor to consider in the context of providing resource-oriented palliative care (PC). Until now, there has been no major review of the existing research on this subject. Of the 3,078 records screened, 281 were examined in detail and 111 were included in the synthesis. A total of 25 different instruments quantitatively assessing the will to live are presented. Most are single-question tools and rate intensity. The underlying concepts and psychometric properties are incompletely explained. Lack of cross-referencing is apparent. The intensity of the will to live is high, even among people with significant health impairment, and is frequently associated with different factors, such as resilience and quality of life. Over a 50-year period, numerous studies have attempted to provide a valid assessment method for WTL without referencing one another, and no consensus exists on this topic. At a time when experts increasingly advocate for resource-oriented approaches to care, the concept of WTL may have important clinical implications, especially at the intersection of geriatrics and PC where patients' WTL is often weakened. **Full text:** https://bit.ly/2FAFYLa

Concerns of parents with children receiving home-based pediatric palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 12 September 2020 – Caring for a child who will die from a life-limiting illness is one of the most difficult experiences a parent may face. Pediatric palliative care (PPC) has grown as a specialty service to address the unique needs of children and families with serious illness. However, gaps remain between the needs of families in PPC and the support received. The objective of this study was to explore the concerns of parents who have a child in home-based PPC. Parents' concerns clustered into four main themes: 1) Ensuring that their child's remaining days were spent living well physically, emotionally, and socially; 2) Uncertainty regarding their child's diagnosis, prognosis, and treatments; 3) Their child's death (e.g., the process of dying and when it will occur); and, 4) The family, including the impact of the child's illness and death on siblings and wanting to cherish as much time together with family as possible. These results highlight salient worries among parents of children in PPC, and point to critical areas for intervention for seriously ill children and the broader family. **Abstract (w. list of references):** https://bit.ly/3khe8Td

Related:

- *OMEGA – JOURNAL OF DEATH & DYING* – 16 September 2020 – '**Factors associated with the location of expected pediatric deaths in the palliative care context.**' This article reviews which factors are associated with pediatric location of death (LoD) and considers some emerging factors important to better facilitate integrative planning. Three overarching areas of consideration related to pediatric LOD planning are identified including health service factors, familial factors and patient factors. The authors present a conceptual model of the factors found to be related to pediatric LoD planning. The limitations that exist with rigorously and empirically studying pediatric LOD preferences are apparent from the dearth of knowledge seen in the field. **Abstract (w. list of references):** https://bit.ly/33DksNZ

Models of palliative care delivery for individuals with cystic fibrosis: Cystic Fibrosis Foundation evidence-informed consensus guidelines

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 September 2020 – Cystic fibrosis (CF) affects more than 70,000 individuals and their families worldwide. Although outcomes for individuals with CF continue to improve, it remains a life-limiting condition with no cure. Individuals with CF manage extensive symptom and treatment burdens and face complex medical decisions throughout the illness course. Although palliative care (PC) has been shown to reduce suffering by alleviating illness-related burdens for people with serious illness and their families, little is known regarding the components and structure of various delivery models of PC needed to improve outcomes for people affected by CF. The U.S. Cystic Fibrosis Foundation assembled an expert panel of clinicians, researchers, individuals with CF, and family caregivers, to develop consensus recommendations for models of best practices for PC in CF. Eleven statements were developed based on a systematic literature review and expert opinion, and address primary PC, specialty PC, and screening for palliative needs. These recommendations are intended to comprehensively address PC needs and improve quality of life for individuals with CF at all stages of illness and development, and their caregivers. **Full text:** https://bit.ly/32Bva8m

N.B. Additional articles on the PC needs of people living with cystic fibrosis noted in Media Watch 10 august 2020 (#678, p.9).

Recommendations for palliative and hospice care in the [U.S.] National Comprehensive Cancer Network guidelines for treatment of cancer

THE ONCOLOGIST | Online – 11 September 2020 – The National Comprehensive Cancer Network (NCCN) cancer treatment guidelines are instrumental in standardizing cancer care; yet, it is unclear how palliative and hospice care are integrated in these guidelines. In this study, the authors reviewed all 53 updated NCCN guidelines for treatment of cancer. They documented the frequency of occurrence of "palliative care" and "hospice care," the definitions for these terms if available, and the recommended timing for these services. "Palliative care" was absent in almost half of NCCN cancer treatment guidelines and was rarely discussed in guidelines for hematologic malignancies. The authors' findings underscored opportunities to standardize timely palliative care (PC) access across NCCN guidelines and underscore opportunities to standardize timely PC access across NCCN guidelines. **Abstract:** https://bit.ly/3mqzW0g

Related:

- *SUPPORTIVE CARE IN CANCER* | Online – 12 September 2020 – **'The silent transition from curative to palliative treatment: A qualitative study about cancer patients' perceptions of end-of-life discussions with oncologists.'** In end-of-life (EoL) conversations, patients described their physicians as being hesitant and evasive and described the conversations themselves as being short, but there was also a certain ambivalence in their own preferences for whether or not to receive information. Becoming aware of one's own palliative situation is a step-by-step process. This transition is not possible through a one-point and one-time EoL conversation. In addition, patients looked for information from a conglomerate of other sources. **Full text:** https://bit.ly/2Zu6ahq

Updated 09.15.2020

Prison Hospice: Backgrounder

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

Photo: Lori Waselchuk. Philadelphia, PA

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

PALLIATIVE MEDICINE | Online – 15 September 2020 – The attention of healthcare professionals is directed mainly towards the recipients of care and often insufficiently towards family carers. However, an effective collaboration between professionals and family carers is vital to provide quality palliative and end-of-life care. Such collaboration is under-studied in a palliative care (PC) context. Four main themes emerged from interpretative phenomenological analysis 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. This qualitative study about the experiences and perceptions of family carers of people with a chronic life-limiting illness living at home regarding the collaboration with different healthcare providers in the last phase of life, showed that family carers experience a lot of possibilities, but perceive missed opportunities as well, for healthcare professionals to effectively collaborate with them for PC. **Abstract (w. list of references):** https://bit.ly/2ZCrBNy

Palliative care provision at a tertiary cancer center during a global pandemic

SUPPORTIVE CARE IN CANCER | Online – 15 September 2020 – The palliative care (PC) program at the Princess Margaret Cancer Centre, Toronto, Canada, provides comprehensive care to patients with advanced cancer and their families, through services including an acute PC unit, an inpatient consultation service, and an ambulatory PC clinic. In the face of a global pandemic, PC teams are uniquely placed to support patients with cancer who also have COVID-19. This may include managing severe symptoms such as dyspnea and agitation, as well as guiding advance care planning and goals-of-care conversations. In tandem, there is a need for PC teams to continue to provide care to patients with advanced cancer who are COVID-negative but who are at higher risk of infection and adverse outcomes related to COVID-19. This paper highlights the unique challenges faced by a PC team in terms of scaling up services in response to a global pandemic while simultaneously providing ongoing support to their patients with advanced cancer at a tertiary cancer center. **Full text:** https://bit.ly/3hCK0zD

Publishing Matters

Predatory journals in the age of COVID-19

HIMMELFARB LIBRARY NEWS (George Washington University) | Online – 16 September 2020 – Amid the COVID-19 pandemic, research papers have been fast-tracked to publication. The pandemic has necessitated significant shifts in the scholarly publishing model that have resulted in research being made available at record speeds and, for most major publishers, available at no cost. Preprints have become mainstream. While many see these as positive changes, there is a darker side to this shift in scholarly publishing. Predatory journals, known for their lack of peer review and willingness to publish any article written by someone able to pay the required Article Processing Charges, have been largely forgotten during the COVID-19 pandemic. Predatory journals are known for their promises of "rapid" publication. But in the time of COVID-19, quick publication has become the norm even among legitimate and highly respected journals. This has led to questions about the quality of peer review and has led to frequent retractions of COVID-19 related articles. In a recent article[1] … states that "the risks to the scholarly community, academic publishing and ultimately public health are at stake when exploitative and predatory publishing are left unchallenged." Academics and the media alike are reading, discussing and trusting content that has not undergone a rigorous peer review process. **Full text:** https://bit.ly/3hLdpb7

1. 'An alert to COVID-19 literature in predatory publishing venues,' *Journal of Academic Librarianship*, 2020;46(5):102187. [Noted in Media Watch 6 July 2020 (#673, p.14)] **Full text:** https://bit.ly/38jWsBy

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EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): https://bit.ly/3iZKjXr

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Media Watch: Editorial Practice

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Distribution

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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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