

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

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Compiled & Annotated by Barry R. Ashpole

The COVID-19 pandemic and recent social justice movements in the U.S., and around the world, have led to an important moment in time for the palliative care community to step back and consider opportunities for expansion and growth.

'A call to action to address disparities in palliative care access: A conceptual framework for individualizing care needs' (p.11), in *Journal of Palliative Medicine*.

U.S.A.

Hospices hitting barriers to integrating behavioral health

HOSPICE NEWS | Online – 9 October 2020 – Advocates have increasingly called for expanded resources to address mental health issues and substance use problems among hospice patients to improve delivery and quality of their care. However, limited research is available for hospice providers looking to integrate psychiatric or mental health services. An estimated 5 to 8 million older adults in the U.S. have one or more mental health conditions, according to research from a 2018 supplement to the *Journal of the American Geriatrics Society*, with projections that this number will triple over the next three decades.¹ As these aging populations reach the end of life, hospices will need to focus on improving access and services aimed at addressing their specific needs. "Behavioral mental health has been a bedrock of hospice and palliative care. It's not an obscure topic, it's right front and center every single day

with patients and families as a core component of care," said Cameron Muir M., chief innovation officer for the National Partnership for Healthcare & Hospice Innovation. "In the advanced illness provider space, it's perhaps a desire for more of a focus, intention and support from a research perspective." <https://bit.ly/2SM4rA8>

Specialist Publications

'Value of advance care directives for patients with serious illness in the era of COVID-19 pandemic: A review of challenges and solutions' (p.6), in *American Journal of Hospice & Palliative Medicine*.

'A pivot to palliative: An interdisciplinary program development in preparation for a Coronavirus patient surge in the emergency department' (p.10), in *Journal of Emergency Nursing*.

1. 'State of the future in global aging, dementia and mental health: Bridging Leadership in science, practice, education and policy,' *Journal of the American Geriatric Society*, April 2018. **Download/view supplement at:** <https://bit.ly/2GMisvx>

Palliative care concepts can help shape providers' COVID-19 response

HOSPICE NEWS | Online – 9 October 2020 – The COVID-19 outbreak ... has underscored the need for clinicians to navigate difficult, often emotional conversations with patients and families about their goals and wishes for the care they receive, including end-of-life and hospice care. Providers that specialize in hospice and palliative care (PC) excel at navigating these sensitive conversations and undergo specific training to develop those skills. PC providers are adept at communicating with patients and families to ensure that they receive care that is consistent with their goals and wishes. The need for goal-concordant care continues even in times of crisis, according to a recent report published in *Caring For the Ages*,¹ particularly in the post-acute and long-term care settings. <https://bit.ly/2Fjw7tk>

1. 'Palliative care amid the pandemic: Resources for PALTC providers and families,' *Caring For the Ages*, 2020;21(6):1. Full text: <https://bit.ly/33K9dET>

Hospices increasingly supplement bereavement care with phone apps

HOSPICE NEWS | Online – 6 October 2020 – Hospices are embracing digital memory sharing platforms that are emerging worldwide to help support patients and their families through the dying process. These evolving technologies have made it possible for families and friends to memorialize loved ones through videos, audio recordings and various other media forms. Hospices are required by the U.S. Centers for Medicare & Medicaid Services to offer bereavement care to patients' families for 13 months after their loved one expires. Hospice social workers, chaplains and volunteers are often roles tying patient families to these services and related services such as memorials, funerals and death doulas. Many hospices extend their grief care beyond their patient populations and offer that same support into the community at large with bereavement camps, support groups and memorial services for those experiencing the loss of a loved one. A rising number of providers are turning to smartphone and tablet apps to enhance their bereavement services. <https://bit.ly/3nujsVM>

Variation in state Medicare implementation of the Affordable Care Act: The case of concurrent care for children

HEALTH AFFAIRS, 2020;39(10):1770-1775. More than 55,000 children die each year in the U.S., and hospice is used for very few of them at the end of their lives. Nearly one-third of pediatric deaths are a result of chronic, complex conditions, and the majority of these children are enrolled in Medicaid because of disability status or the severity of their disease. Changes in Medicaid/Children's Health Insurance Program regulations under Section 2302 of the Affordable Care Act require all state Medicaid plans to finance curative and hospice services for children. The section enables the option for pediatric patients to continue curative care while enrolled in hospice. The authors examined state-level implementation of concurrent care for Medicaid beneficiaries and found significant variability in guidelines across the U.S. The implementation of concurrent care has fostered innovation yet has added barriers to how pediatric concurrent care has been implemented. **Abstract (w. link to references):** <https://bit.ly/3d45RPQ>



[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

International

COVID-19 is helping wealthy countries talk about death

THE ECONOMIST | Online – 10 October 2020 – Until this year many New Yorkers had never heard of Hart Island, where the city's unclaimed dead are buried. Then, in the midst of the pandemic, video of contractors digging long trenches there went viral. Around 120 bodies were sent to the tiny islet every week, as burial grounds and crematoriums struggled to keep pace with COVID-19. COVID-19 has caused more than a million recorded deaths, most not in developing countries like Brazil, but in developed ones. That cuts against a long-standing trend. Since World War II, wealthy states have had few massive episodes of premature fatality. Their cultures have tended to push mortality out of sight, into hospitals and out of polite conversation. Now, the pandemic is nudging people in the rich world to adopt the open and pragmatic approaches to death more typical in developing countries, where poverty, poor healthcare, dangerous roads and armed conflict keep people on familiar terms with the grim reaper. <https://econ.st/2SICcT0>

Specialist Publications

'Education is an important factor in end-of-life care: Results from a survey of Brazilian physicians' attitudes and knowledge in end-of-life medicine' (p.7), in *BMC Medical Education*.

'Palliative care in rural and remote areas: Challenges facing rural nurses in palliative cancer care in the far North of Norway' (p.11), in *Nordisk Sygeplejeforskning*.

'Family members' expressions of dignity in palliative care: A qualitative study' (p.11), in *Scandinavian Journal of Caring Sciences*.

Palliative care may adversely affect the profit of some healthcare institutions

INDIA | *Express Healthcare* (Mumbai) – 9 October 2020 – There are many reasons why the growth of palliative care (PC) in the country is so slow. It demands a major paradigm shift in the way the current healthcare system works. PC is not a simple concept which can be taught by a one-page protocol – unlike an immunisation schedule. PC is prevention and treatment of serious health related suffering, which has many elements including pain and other physical symptoms, emotional issues including depression, anger, guilt and anxiety, social issues of huge relevance to this country and spiritual issues – not those related to religion, but existential questions like the meaning and purpose of life. Such a change may not be convenient for the healthcare system. The delay in incorporating essential PC in the medical education system is another factor; most elements of PC including basic pain management, end-of-life care, attitude, ethics and communication came into the curriculum only effective from 2019. It will take a whole generation to translate that curriculum change into action. The draconian Narcotics Drugs & Psychotropic substance act of 1985 posed a huge barrier to access to essential medicines including morphine for pain relief. It took advocacy for a period of 19 years and finally the Indian Parliament in 2014 changed it. But now, 29 states and six union territories have to individually implement it. In India, laws and policies do not get translated to action automatically. <https://bit.ly/3nwAIJP>

The logo for Pallium India features the word "PALLIUM" in a large, bold, sans-serif font. The letter "A" is stylized with a green circular graphic element. Below "PALLIUM" is the word "INDIA" in a smaller, bold, sans-serif font.

N.B. Additional articles on PC in India noted in Media Watch 15 June 2020 (#670, pp.5-6).

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Palliative care can't survive on "cake and op-shops"

NEW ZEALAND | *New Zealand Herald* (Auckland) – 7 October 2020 – New Zealand's death rate is set to climb by 50% in the next 20 years as the population ages. New Zealand's hospices aren't equipped to look after so many dying patients – and nor are hospitals. Mary Schumacher, of Hospice New Zealand, said this was not about the future, but about now. "I think we really are behind," she said. "We need to have a clear focus that everybody in New Zealand, irrespective of setting, deserves the very best possible palliative care (PC) and end-of-life care." Each year the New Zealand government provides about \$78 million, and the last proper increase in funding was the 2015 budget... There's \$155 million a year in costs, meaning the \$77-million shortfall is made up through fundraising. Professionals say now is the crucial time for a rethink and a restructure, and PC must be properly integrated into the health system and budget, or the nation risks sidelining people, particularly in rural settings. <https://bit.ly/3jDoMUe>

Give Me a Break

U.K. (England) | Together for Short Lives – 7 October 2020 – The pressure on families caring for a seriously ill child with complex needs is immense. The burden of caring for a child 24/7 and the knowledge that your child will die young can be too much to bear, so having access to regular short breaks is vital to relieve this stress, spend time as a family, and do the things that other families do. Yet local authority funding for short breaks for children's hospices was cut by 12% in 2019-2020. In a new study published by Together for Short Lives, 'Give Me a Break,' researchers report that: 1) Reduced stress leads to improved physical health among carer parents, which in turn leads to reduced number of GP visits and cost-savings to the health system; 2) Reduced stress leads to improved mental health among carer parents, which in turn reduces the use of mental health services and the associated costs; 3) Improved work attendance: this can be measured in reduced number of sick days taken, which ultimately leads to increased productivity and additional tax revenue; and, 4) Short breaks are also likely to have a positive impact on siblings and reduce the risk of parental relationships breaking up. **Download/view report at:** <https://bit.ly/3izNNOJ>

Survey finds broad acceptance of palliative care among Taiwan public

TAIWAN | *Focus Taiwan* (Taipei) – 6 October 2020 – Around seven in 10 Taiwanese adults support the concept of hospice care and believe that emergency medical treatment may not always be the right answer for terminally ill patients, according to the results of a recent survey. The survey ... found high levels of support for issues such as patients' rights and palliative care for the terminally ill. 72% of the survey respondents said they would inform their parents in honest terms if one of them received a terminal diagnosis, compared to only 55.8% 10 years ago ... and 75% of those aged 40 and above said emergency medical treatment is not always the right move for terminally ill patients. Regarding hospice care, some 77.4% of the respondents said they were familiar with the concept, compared to only 46% a decade ago, the survey found. Of those, 73.5% said they approved of the aims of hospice care, with levels of support rising again in conjunction with the age of the respondents. Despite the generally high levels of awareness, only 43.3% of the respondents said they felt "prepared to accept death." Perhaps illustrating that figure, 97% said they believe in end-of-life planning, but nearly 60% said they had yet to make any concrete plans for their own deaths. <https://bit.ly/3jBe2G7>

(台灣) 安寧照顧基金會
Hospice Foundation of Taiwan

Noted in Media Watch 25 November 2019 (#641, p.3):

- TAIWAN | *Focus Taiwan* (Taipei) – 22 November 2019 – 'Taiwan allows patients of 11 rare diseases decision-making power.' Taiwan's Ministry of Health & Welfare has included 11 rare diseases in the clinical conditions under which the country's Patient Right to Autonomy Act is applicable, giving those suffering from such illnesses the right to decide whether to continue life support or other treatment. The Act, the first of its kind in Asia ... offers people the right to decide in advance what medical treatment or healthcare they accept when they are terminally ill, in an irreversible coma, in a permanent vegetative state, suffering from severe dementia, or in other disease conditions that the authorities determine are unbearable or incurable. <http://bit.ly/2OEMS2D>

COVID-19: Amnesty demands immediate inquiry into care home residents “abandoned to die”

U.K. (England) | *The Independent* (London) – 5 October 2020 – The human rights of older people have been violated in England’s care homes because of a series of “shockingly irresponsible” government decisions in response to the Coronavirus pandemic, a report has found.¹ Human rights campaigners Amnesty International demanded an immediate independent public inquiry, after a report by the group’s crisis response team found that thousands of older people were effectively “abandoned to die.” The report found that the death toll in England’s care homes was “entirely avoidable” and that residents’ rights to life, health and non-discrimination were violated. It raised particular concern about the misuse of “do not attempt resuscitation” orders, after witnesses gave evidence that local GPs and clinical commissioning groups had requested their insertion into residents’ files on a blanket basis. Interviews with care home managers and staff uncovered accounts of a “complete breakdown” of systems in the first six weeks of the crisis, with the government ordering the discharge of 25,000 people from hospitals into homes in order to clear

National Health Service beds... The report found that between 2 March and 12 June some 28,186 “excess deaths” were recorded in care homes in England, with over 18,500 residents confirmed to have died with coronavirus during this period. <https://bit.ly/3ljKLAA>

Extract from Amnesty International report

Obtaining access to GPs got markedly more challenging during the pandemic, as GPs throughout the country switched to phone/online consultations and stopped visiting care homes. National Health Service England advised GPs to begin the roll out of remote consultations on 17 March 2020, prioritising vulnerable groups, but limiting face-to-face consultation to only “when absolutely necessary.” However, guidance on 15 April stated that “end-of-life care, including palliative care, must continue to be planned in a holistic way involving social care, community nursing, general practice, occupational therapy, and others” – including “access in people’s homes and care homes to professionals and equipment that support this.”

1. ‘As if Expendable: The U.K. Government’s Failure to Protect Older People in Care Homes During the Covid-19 Pandemic,’ Amnesty International, October 2020. **Download/view at:** <https://bit.ly/2SzaLLj>

Noted in Media Watch 20 July 2020 (#675, p.12):

- *BRITISH MEDICAL JOURNAL* | Online – 15 July 2020 – ‘**COVID-19: Government to issue new guidance on DNAR orders after legal challenge.**’ The government ... will publish new national guidance for England on “do not attempt resuscitation” orders, amid concern that blanket bans on CPR were being imposed by some healthcare providers during the COVID-19 pandemic. The move comes after a threat of legal action against the government by the daughter of a man who successfully fought to establish that patients have a right to be consulted on resuscitation. In May she launched a High Court challenge against the health secretary over the government’s failure to issue clear national guidance to ensure that patients’ rights in relation to do not attempt resuscitation orders were protected. **Full text:** <https://bit.ly/2Wkoqlo>

Specialist Publications

A feasibility study of a volunteer navigation program in the palliative context

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 8 October 2020 – Older persons with serious illnesses living in rural communities are an underserved population. They often live with heavy symptom burden and poor quality of life with limited access to resources. Nav-CARE (Navigation: Connecting Accessing Resourcing and Engaging) was developed to specially train and mentor volunteer navigators who help connect older persons with serious illness to the resources and information they need. Volunteer navigators and older persons reported Nav-CARE was easy to use, feasible and acceptable. The majority of older persons agreed or strongly agreed that they were satisfied with the navigation services (100%; 8/8), that navigation services were important to them (87%; 7/8), that they would recommend the program

Cont.

to someone else (87%; 7/8), and would participate in the program again (75%; 6/8). Similarly, volunteer navigators reported 100% (9/9) satisfaction with the program, 100% (9/9) would recommend it to others, and 67% (6/8) would participate again. Nav-CARE appears to be a feasible, acceptable, and satisfactory program for older persons with serious illness and volunteer navigators. **Abstract (w. list of references):** <https://bit.ly/3iljiq6>

Noted in Media Watch 25 May 2020 (#667, p.6):

- *BMC PALLIATIVE CARE* | Online – 22 May 2020 – ‘**Implementing volunteer-navigation for older persons with advanced chronic illness: A knowledge to action study.**’ This study highlights the importance of community-based champions for the success of volunteer-led initiatives and the critical need for support and mentorship for both volunteers and those who lead them. Although the underutilization of hospice has been widely recognized, it is vital to recognize the limitations of their capacity. Initiatives such as Nav-CARE, designed to enhance their contributions to palliative care (PC), need to be accompanied by adequate resources. This study illustrates the need to think carefully about the language and role of hospice societies as PC moves toward a public health approach to care. **Full text:** <https://bit.ly/2ZwJ0l0>

Value of advance care directives for patients with serious illness in the era of COVID-19 pandemic: A review of challenges and solutions

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 October 2020 – At end-of-life, when faced with poor prognosis for a meaningful health-related quality of life, most patients indicate their preference to abstain from aggressive, life-sustaining treatments. Patients whose wishes are left unsaid often receive burdensome life sustain therapy by default, prolonging patient suffering. The COVID-19 pandemic has strained healthcare resources and raised the need for prioritization of life-sustaining therapy. This highlights the urgency of ACDs more than ever. Despite ACDs’ potential to provide patients with care that aligns with their values and preferences and reduce resource competition, there has been relatively little conversation regarding the overlap of ACDs and COVID-19. There is low uptake among patients, lack of training for healthcare professionals, and inequitable adoption in vulnerable populations. However, solutions are forthcoming and may include electronic medical record completion, patient outreach efforts, healthcare worker programs to increase awareness of at-risk minority patients, and restructuring of incentives and reimbursement policies. This review carefully describes the above challenges and unique opportunities to address them in the COVID-19 era. If solutions are leveraged appropriately, ACDs have the potential to address the described challenges and ethically resolve resource conflicts during the current crisis and beyond. **Abstract (w. list of references):** <https://bit.ly/3iCrYxY>

Briefing a children’s hospice: Bridging the evidence gap and redefining value in contemporary healthcare design

ARCHITECTURAL RESEARCH QUARTERLY | Online – 5 October 2020 – Knowledge produced within the field of evidence-based design seeks credible data to support decision-making in the architectural design process. When directed towards the design of healthcare settings, such knowledge can support both the optimisation of patient healing and the improvement of staff performance in ways that correlate positively with patient safety and well-being. Spatial configurations that improve co-worker proximity, visibility, and communication can have a positive influence on staff perceptions of work culture, available support, and workplace safety that, in turn, support the delivery of patient care. Spatial proximities also have a direct influence on the types and frequencies of socialisation that will take place within spaces between patients, family members, and staff. This can support or hinder the formation of social support networks that can assist patients and family members to cope with stress, and healthcare workers to cope with stress and work-related grief. Evidence-based design researchers have also argued that design can be utilised to improve infection control, reduce falls, and minimise errors in medication dispensing. A clear disparity exists, however, in the quantity of evidence available to guide the designers of hospital-based palliative care and hospice facilities relative to general hospitals. **Abstract:** <https://bit.ly/3nAfYAU>

N.B. Selected articles on the relationship between the architecture of healthcare facilities and the quality of hospice and palliative care noted in Media Watch 21 September 2020 (#684, pp.2-3).

Integration of palliative care in services for children with life-limiting neurodevelopmental disabilities and their families: A Delphi study

BMC HEALTH SERVICES RESEARCH | Online – 8 October 2020 – The expert opinion of the Delphi panel is that currently, services to young children with life-limiting neurodevelopmental disabilities (LLDNN) and their families are under-funded and under-resourced, with definite gaps in some areas of service provision as well as poor communication between acute and community-based services. While the expert panel agrees on what the goals-of-care for this population of children and their family are, there is less consensus regarding the changes to current services that are required to achieve these goals and improve services to this population of children and their families. This makes acting to improve services to young children with LLNDD even more complex, though the findings of this study do offer specific recommendations that would contribute to more effective services. **Full text:** <https://bit.ly/3iIFLTG>

Education is an important factor in end-of-life care: Results from a survey of Brazilian physicians' attitudes and knowledge in end-of-life medicine

BMC MEDICAL EDUCATION | Online – 2 October 2020 – According to the Asociación Latinoamericana de cuidados paliativos, Brazil offers only 0.48 palliative care (PC) services per 1 million inhabitants.¹ In 2012, no accredited physicians were working in PC, while only 1.1% of medical schools included PC education in their undergraduate curricula. As a reflection of the current scenario, little research about end-of-life (EoL) care has been published so that studies addressing this subject in the Brazilian setting are crucial. This study demonstrates that Brazilian physicians lack training and knowledge in EoL medicine. It also shows that training is considered to be a key factor in overall EoL care knowledge. This study is an important wake-up call for the importance of PC training in Brazilian medical schools and residency programs. **Full text:** <https://bit.ly/30z8Zyf>

1. 'Atlas de Cuidados Paliativos de Latinoamérica,' Asociación Latinoamericana de Cuidados Paliativos, 2012. [Noted in Media Watch 7 January 2013 (#287, p.8)] <https://bit.ly/3ldpJmu>

N.B. Click on pdf icons to access either Portuguese, Spanish or English language version of the atlas.

Noted in Media Watch 20 August 2018 (#577, p.13):

- *REVISTA BRASILEIRA DE GERIATRIA E GERONTOLOGIA*, 2018;21(3):261-271. '**Palliative care: A proposal for undergraduate education in medicine.**' In Brazil, the Universidade Federal de São Paulo was the first medical school to offer palliative care (PC) courses... In 2003, a compulsory PC discipline was created at the Universidade de Caxias do Sul. Despite these examples of approaches to PC in education, which were later followed by other universities, there is a lack of correlation between the provision of instruction in PC and the perception of its importance in most medical schools. Such schools have described insufficient time, a lack of faculty expertise and the time-consuming demands of multiple interests as the reasons for the lack of curricular under-representation of PC. **Full text:** <https://goo.gl/5wTrSt>

N.B. Click on pdf icons to access either Portuguese or English language versions of this article.

Noted in Media Watch 18 June 2018 (#568, p.12):

- *REVISTA BRASILEIRA DE EDUCAÇÃO MÉDICA*, 2018;42(2). '**End-of-life paradigm in medical training: Attitudes and knowledge about death and palliative care.**' In Brazil, palliative medicine has recently been promoted to the category of medical specialty, obliging Brazilian medical schools to review the educational concepts associated to end-of-life (EoL) care. The scholar's view of death may determine their inner disposition, values, concepts, and prejudices regarding death and dying and determine their performance as a professional. Thus, medical education programs must emphasize not only the theoretical-technical aspects in palliative care, but also the emotional climate that involves the medics' attitudes and actions in EoL situations. **Full text:** <https://goo.gl/d2ghrQ>

N.B. Portuguese language article.

N.B. Brazil was ranked 42nd of 80 countries surveyed in the '2015 Quality of Death Index: Ranking Palliative Care Across the World,' The Economist Intelligence Unit (commissioned by the Lien Foundation of Singapore), October 2015. [Noted in Media Watch 12 October 2015 (#431, p.6)] **Download/view at:** <https://bit.ly/30waHAX>

Information sharing challenges in end-of-life care: A qualitative study of patient, family and professional perspectives on the potential of an electronic palliative care co-ordination system

BMJ OPEN | Online – 5 October 2020 – There are only a limited number of qualitative studies exploring attitudes towards and use of an electronic palliative care co-ordination system (EPaCCS). The findings of this study support those of a recent systematic review that identified the burden of inputting data and information technology (IT) systems as the main challenge to implementation of EPaCCS.¹ A key finding of this study was that introduction of an EPaCCS alone does not provide a solution to some of the current difficulties regarding interdisciplinary management of end-of-life (EoL) patients in the community. An EPaCCS will only facilitate access to patient information, the utility of which is largely dependent on its quality; improving access to advance care planning (ACP) documentation is not going to improve care if the information recorded within them is of poor quality or insufficient detail, or has not been completed. This demonstrates a need for investment in training for health and social care professionals in ACP discussions and documentation to instill confidence and improve quality. This article highlights concerns regarding the infrastructure required to support an EPaCCS including: demand on already stretched professionals, technology provision required to enable access and continued support to ensure the system is updated. Ensuring appropriate infrastructure is in place has emerged as a challenge in the implementation of coordinated records for EoL patients in the U.K. and U.S. contexts. **Full text:** <https://bit.ly/3liSajZ>

1. 'Electronic palliative care coordination systems (EPaCCS): A systematic review,' *BMJ Supportive & Palliative Care*, published online 8 May 2019. [Noted in Media Watch 20 May 2019 (#614, p.8). **Full text:** <http://bit.ly/2Jvp5kQ>

How do geriatric principles inform healthy aging?

CLINICS IN GERIATRIC MEDICINE, 2020;36(4):559-567. Healthy aging long has been held as a core belief and priority of geriatrics, yet clinical, scholarly, and advocacy efforts have not kept pace with attention to multimorbidity and end-of-life care. With an aging US population and trends toward higher rates of lifestyle diseases, there is imperative for geriatricians to engage in efforts to promote healthy aging. Lifestyle medicine offers an evidence-based approach to healthy aging at any point in the life span. This emerging branch of medical practice has synergistic principles and frameworks with the field of geriatrics, which should further empower geriatricians to engage in promoting healthy aging. **Abstract (w. list of references):** <https://bit.ly/3lcLvqA>

N.B. Selected articles on the “potential overlap” of geriatric medicine and palliative and end-of-life care noted in Media Watch 6 January 2020 (#647, pp.6-7).

Care to the end: A retrospective observational study of aged care facility residents transferred to hospital in the last day of life

INTERNAL MEDICINE JOURNAL | Online – 5 October 2020 – Whilst transfer of aged care facility (ACF) residents to an acute hospital is sometimes necessary, for those at end-of-life (EoL) this can cause fragmented care and disruption. This study explores the characteristics of ACF residents transferred to hospital in the last 24-hours of life and factors that may influence this decision, including access to medical review, advance care planning (ACP) and pre-emptive symptom management prescribing; an area not previously researched. The commonest reasons for transfer were dyspnoea (46%) and altered conscious state (32%), and commonest cause of death was pneumonia (37%). Some form of ACP documentation was available in 48%. Of the 86 (58%) patients who required injectable opioid for symptom management in hospital, only 7(8%) had this pre-emptively prescribed on their ACF medication chart. Appropriate decision-making around hospital transfers and EoL care for ACF residents may be influenced by access to professionals able to diagnose dying and access to appropriate symptom management medications. ACP is important, but often requires the aforementioned to be enacted. **Abstract:** <https://bit.ly/3jzGdF8>



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Coordination in palliative home care: Who plays the key role?

INTERNATIONAL JOURNAL OF INTEGRATED CARE, 2020;20(3):15. This study [carried out in four Swiss cantons] reveals that there exists considerable ambiguity concerning who plays a key role in care coordination amongst professionals and family members of palliative patients in palliative home care settings. Moreover, the findings reveal that this ambiguity can be attributed to the fact that the key coordinator role is often context dependent, rather than a fixed position. Moreover, the findings affirm previous studies, which highlight that poorly defined professional roles contribute to poor coordination between professionals and poor quality of care. Importantly, the results shed light on the negative impact that ambiguity concerning key coordinators has on family members, who consequently take on care coordination roles themselves and are over-burdened and financially under-supported. The results ultimately stress the importance of clearly communicating key roles to all members of the palliative teams, including relatives, as well as highlighting the need for adequately supporting those who are in coordinating positions. The outcomes of this study are of interest to healthcare practitioners, policymakers and researchers involved in the support of care coordination in palliative home care settings. Crucially, future initiatives to en-

courage the effective communication of roles and to consolidate standardized palliative care team understandings regarding care coordination roles ought to be invested in. Likewise, ensuring that family members of palliative patients are ensured the appropriate education, psycho-social and financial support that reflects their involvement in care coordination warrants special attention. **Full text:** <https://bit.ly/2Ss2by8>

Associations between hospice care and “scary” family caregiver experiences

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 October 2020 – Dying hospice patients may have rapidly emerging needs the hospice team cannot immediately meet, exposing family caregivers (FCGs) to fright-inducing (i.e., scary) situations. Research is needed to understand how better to support FCGs of hospice patients to enable them to cope with common, distressing symptoms of dying cancer patients. Hospice clinicians providing additional education and training about these symptoms might enable caregivers to better care for dying loved ones and reduce the stresses of end-of-life caregiving. **Abstracts (w. list of references):** <https://bit.ly/36JvDYC>

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>

Integrative palliative care: A new transformative field to alleviate suffering

JOURNAL OF ALTERNATIVE & COMPLEMENTARY MEDICINE, 2020;26(9):761-765. The articles included in this special issue focus on the overarching goal of integrative palliative care (PC) – to reduce the suffering of people with serious illness and their families. The articles cover topics that are imperfectly addressed by conventional PC approaches and provide palliative indications for complementary modalities that are used in varied populations. Assessed together, the articles strengthen the assertion that formal attention to the amplification of integrative PC can alleviate suffering and optimize the health and well-being of people with serious illness across the life course through high-quality whole-person integrative healthcare. **Full text:** <https://bit.ly/2SyNwRz>

N.B. Journal contents page: <https://bit.ly/33ydCus>

Cont.

Noted in Media Watch 6 august 2018 (#575, p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online –1 August 2018 – ‘**Complementary and alternative medicine in hospice and palliative care: A systematic review.**’ When conventional therapies do not provide adequate symptom management or produce their own adverse effects, patients, families and caregivers may prefer complementary or alternative approaches in their care. Out of 4,682 studies, 17 were identified for further evaluation. Therapies included acupressure, acupuncture, aromatherapy massage, breathing, hypnotherapy, massage, meditation, music therapy, reflexology, and reiki. Many demonstrated a short-term benefit in symptom improvement from baseline with complementary and alternative medicines... **Abstract (w. link to references):** <https://goo.gl/9tTspf>

A pivot to palliative: An interdisciplinary program development in preparation for a Coronavirus patient surge in the emergency department

JOURNAL OF EMERGENCY NURSING | Online – 22 August 2020 – During a time of unprecedented insecurity brought about by **COVID-19**, emergency department (ED) clinicians were called on to identify patients’ goals and care preferences with a lack of patient family/support presence and with limited training regarding palliative care (PC) principles. As the role of PC in the ED has been explored, yet not well defined, PC clinicians were also challenged to learn the workflow and practices of the ED to best serve this patient population. The authors provide a template of their process aimed to improve PC delivery in the ED through educational and support resources. Rapid learning processes and communication between nurse representatives from the two specialties allowed for the development of both in-the-moment support and educational tools. The implementation of this program demonstrates that an interdisciplinary and collaborative approach to addressing these challenges can yield a supportive program during a surge in the number of patients testing positive for COVID-19, while developing a working relationship between emergency nursing and PC. By working together in a crisis, nurses within these two specialties found a path to supporting patient care that will last beyond the pandemic itself. **Full text:** <https://bit.ly/3jEW8Ch>

Noted in Media Watch 7 September 2020 (#682, p.8):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 30 August 2020 – ‘**The experience of emergency department providers with embedded palliative care during COVID-19.**’ Of the clinicians that had interacted with palliative care (PC) [i.e., survey respondents], 100% indicated a benefit of having PC involved. These included freeing up emergency department (ED) clinicians for other tasks (89%), helping them feel more supported (84%), changing the patients care trajectory (67%), and contributing to clinician education (57%) and skills (49%). ED clinicians’ perception of embedded PC was overall positive, with an emphasis on the impact related to task management, enrichment of PC skills, providing support for the team, and improved care for ED patients. **Abstract (w. list of references):** <https://bit.ly/3bdbh2Z>

Noted in Media Watch 10 August 2020 (#678, p.4):

- *ADVANCED EMERGENCY NURSING JOURNAL*, 2020;42(3):215-224. ‘**Bringing palliative care downstairs: A case-based approach to applying palliative care principles to emergency department practice.**’ Although the emergency department (ED) may not be traditionally thought of as the ideal setting for the initiation of palliative care, it is the place where patients most frequently seek urgent care for recurrent issues such as pain crisis. Even if the patients’ goals-of-care are non-aggressive, their caregivers may bring them to the ED because of their own distress at witnessing the patients’ suffering. ED providers, who are trained to focus on the stabilization of acute medical crises, may find themselves frustrated with repeat visits by patients with chronic problems. **Abstract:** <https://bit.ly/33rxeRr>



Media Watch: Access Online

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

A call to action to address disparities in palliative care access: A conceptual framework for individualizing care needs

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 October 2020 – Palliative care (PC) is a values-driven approach for providing holistic care for individuals and their families enduring serious life-limiting illness. Despite its proven benefits, access and acceptance is not uniform across society. The genesis of PC was developed through a traditional Western lens, which dictated models of interaction and communication. As the importance of PC is increasingly recognized, barriers to accessing services and perceptions of relevance and appropriateness are being given greater consideration. The COVID-19 pandemic and recent social justice movements in the U.S., and around the world, have led to an important moment in time for the PC community to step back and consider opportunities for expansion and growth. This article reviews traditional models of PC delivery and outlines a modified conceptual framework to support researchers, clinicians and staff in evaluating priorities for ensuring individualized patient needs are addressed from a position of equity, to create an actionable path forward. **Abstract:** <https://bit.ly/3jl1ywb>

Palliative care in rural and remote areas: Challenges facing rural nurses in palliative cancer care in the far North of Norway

NORDISK SYGEPLEJEFORSKNING, 2020;3(10):150-163. In Finnmark, the northernmost county of Norway, many villages are remote and scattered between vast stretches of uninhabited land, with mountain crossings that are often closed in winter or where one can only drive in single file behind a snow plough. This may mean periodic total isolation and daily challenges with long distances to other professionals and hospitals. These special circumstances mean that nurses must act more independently than elsewhere. The main finding of the study is that the nurses experienced themselves as being alone geographically and professionally in their practice of palliative care. The established infrastructure for performing advanced nursing in patients' homes is poorly adapted to the geographical and professional situation in rural areas such as Finnmark, and suboptimal information about patients arriving from hospitals can compromise the quality of care. Advanced nursing is performed when specialists are far away and there is no palliative team, and they care for patients who are often their family members, friends and acquaintances, which involves role ambiguity and a risk of over-involvement. The study shows that requirements to enhance palliative cancer care are to establish palliative teams, discharge summaries present in transition, the necessary drugs and medical equipment for several days, and relevant training of personnel. **Abstract:** <https://bit.ly/3iAgMCd>

Family members' expressions of dignity in palliative care: A qualitative study

SCANDANAVIAN JOURNAL OF CARING SCIENCES | Online – 6 October 2020 – This study contributes to the knowledge of family members' expressions of dignity. Living with the two-headed paradox has an impact on their relationship with the ill person and other family members, as well as with healthcare professionals. Living as a respected human being in relation to oneself and to others can be achieved through maintaining one's identity, feeling connected to others and being comfortable in the situation. Family members' sense of dignity can be preserved and affected by their own and other persons' attitudes and behaviours. Some clinical implications can be suggested how to provide dignified care encompassing the family members. One fundamental caring activity is to invite and encourage them to share their thoughts and feelings of dignity and to acknowledge their competence in the current situation. By being aware of the complexity, and through recognising the reciprocal impact, healthcare professionals can offer tailored support both to family members and to the ill person. In this light, it is of importance for family members not to be trapped in the role of a formal carer. Thus, professionals need to be careful and co-create caring activities with family members and significant others, enabling them to live as fully as possible. However, further research is needed to explore how the two-headed paradox impacts all those involved in palliative care, and also on how family members and ill persons affect each other's sense of dignity, as well as the potential consequences. **Full text:** <https://bit.ly/3lkd5SS>

Biomedicalization of end-of-life conversations with medically frail older adults...

SOCIAL SCIENCE & MEDICINE | Online – 9 October 2020 – The common practice of delaying and/or avoiding end-of-life (EoL) conversations with medically frail older adults is an important clinical issue. Most research investigating this practice focuses on clinician training and developing conversation skills. Little is known about the socio-political factors shaping the phenomenon of EoL conversations between clinicians and medically frail older patients. Using the critical lens of biomedicalization, the authors consider how two dominant discourses, successful aging and frailty, and subsequent constructions of bodies as malleable or senescent, shape patient subjectivities and influence normative expectations about appropriate healthcare conversations and the consumption of biomedicine for medically frail adults. They highlight the uneven ways medically frail older adults are clinically positioned as successful or frail agers and briefly discuss how gender, class, and race may impact this tension and ambiguity. The authors conclude by arguing that EoL conversations with medically frail older adults is constrained by the pervasiveness of the successful aging discourse and the tendency within medical institutions to construct older bodies as malleable and in need of medical intervention to promote health and longevity. **Abstract:** <https://bit.ly/2SE2lwK>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *WELLCOME OPEN RESEARCH* | Online – 1 October 2020 – **‘Practical and ethical complexities of medical assistance in dying: Examples from Quebec.’** The authors interviews with physicians revealed conflicting views about the ethical permissibility of medical assistance in dying (MAiD). However, they also exposed nuances within these opinions, which did not always come across either as a full rejection or as a wholehearted embrace of the practice. A close reading of the interviews uncovered preoccupation with excessive treatment and medical interventionism, the practicalities of work and the realities of objection. The apparent absence of time, between aggressive life-prolonging measures and deliberately causing death, may speak to a medico-social denial of death, by which the period of decline, where there is no longer an objective of cure, appears unacceptable. It may also be indicative of the effects of financial austerity having contributed to underdeveloped, underfunded and unequally distributed palliative care services. If we grant that aggressive medical treatment can be a source of suffering and pain, liable to be experienced as unbearable if no longer serving life-ameliorating purposes, this may generate demands for MAiD that might not have arisen or would arise at a later stage, had a more supportive treatment course been adopted. Indeed, for some, the practice of aggressive treatment until death makes assisted dying stand out as the (only) humane option. For others, it raises practical questions of ethical consequence relating to the evaluation and determining criteria of MAiD eligibility. Importantly, however, Seller *et al* raises the question of what MAiD really means to the population when patients requesting it simultaneously have resuscitation orders in place.¹ So too does the consistent description of patients desiring MAiD as possessing a particular independent or controlling character. These findings indicate that MAiD is not experienced as ethically equivalent to other end of life options, as some seem to suggest. **Full text:** <https://bit.ly/2HP1FIf>

The empirical materials used in this article stem from a larger qualitative interview study with 29 professionals involved with palliative care (PC) and/or assisted dying in Flanders (Belgium), Oregon (U.S.) and Quebec (Canada). The objective of this study was to explore the relationship of PC with assisted dying in these settings, from the perspective of PC clinicians and other professionals involved in both assisted dying and PC, going beyond the official statements about anticipated or feared impacts of assisted dying legalisation to learn about how this unfolds in practice.

1. Situating requests for medical aid in dying within the broader context of end-of-life care: Ethical considerations, *Journal of Medical Ethics*, published online 21 November 2018. [Noted in Media Watch 26 November 2018 (#591, p.20). **Abstract:** <https://goo.gl/1SjstG>

Publishing Matters

Avoiding publishing in predatory journals: An evaluation algorithm

JOURNAL ON EFFICIENCY AND RESPONSIBILITY IN EDUCATION AND SCIENCE, 2020;3(3):154-163. Academics and scholars need to publish their research results. In addition, they are required to publish scientific papers to prove their research commitment and to achieve certain academic titles in higher education institutions. Globally, there are many scientific journals of well-known publishing houses/universities, which offer opportunities to publish scientific work. One of the recent topics in academic circles is the increasing number of invitations to publish articles via quick procedures, without going through the adequate review process. This phenomenon is threatening academic integrity, as these publishers/journals aim at financial benefits and not contributing to scientific development and progress. There is a gap in the knowledge of the scientific researchers regarding the journal selection to publish their work. Some of them are still unintentionally publishing in such journals, mainly as a lack of information about them. The main purpose of this study is awareness-raising, warning, and guidance of scientific researchers, particularly young researchers by providing information on how to avoid submitting manuscripts in these journals. To achieve this, the author consulted the recent literature and practices of different countries, summarized the most used tools/methods to identify predatory publishers and journals, and lastly, developed a guiding algorithm for evaluating them. **Abstract (w. list of references):** <https://bit.ly/30AX56Y>

Media Watch: Editorial Practice

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

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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.

Media Watch: Access on Online

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://bit.ly/3ddX0v7>

[Scroll down to 'Media Watch: Nursing']

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

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

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

Asia



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

[Scroll down to 'Media Watch']

Australia

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

Canada



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

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

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

Europe



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

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

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

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

Barry R. Ashpole, Ontario CANADA

e-mail: barryashpole@bell.net