

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

Without a clear operational consensus on the meaning of the phrase within the medical community, “goals-of-care” often is used as a vaguely defined “buzz phrase” to connote that a patient is not doing well clinically.

'The pitfalls of utilizing “goals-of-care” as a clinical buzz phrase: A case study and proposed solution' (p.10), in *Palliative Medicine Reports*.

Canada

Are Canadians ready to accept psychedelics in palliative care?

THE GLOBE & MAIL | Online – 11 October 2020 – In August 2020, Health Canada granted a special exemption to allow four terminally ill patients to take psilocybin. Psilocybin is not legally sold in Canada. In illegal markets it circulates as magic mushrooms, but researchers suggest that psychedelic drugs such as psilocybin have therapeutic potential for easing anxieties, particularly those associated with dying. The recent allowance from Health Canada signals a change in that view. It brings Canada into a growing international conversation about the revitalization of psychedelics, both in research and as a viable mental health treatment option. Psychedelics ... are often directed as a single-use therapy. They offer a consciousness-raising or pain-confronting approach, not an experience that is necessarily to be repeated, and not an approach meant to dampen or numb pain but to address it through

confrontation. In some ways, this approach is an entirely different way of thinking about mental anguish. Palliative care (PC) has also emerged as a hot spot in our healthcare system. The development of PC and dedicated hospital spaces for dying have helped generate a conversation around dying with dignity, something that can be extended to include the use of psychedelics for terminally ill patients. <https://tgam.ca/34RxZ51>

Specialist Publications

'A mixed-method evaluation of a volunteer navigation intervention for older persons living with chronic illness (Nav-CARE): Findings from a knowledge translation study' (p.5), in *BMC Palliative Care*.

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Noted in Media Watch 10 August 2020 (#678, pp.1-2):

- CTV NEWS | Online – 4 August 2020 – **‘Four terminally ill Canadians get special exemption to use psychedelic therapy.’** In a landmark decision, four Canadians suffering from terminal illnesses have been approved to receive psilocybin therapy to treat their anxiety -- marking the first time that a legal exemption has been given in Canada for patients to access psychedelic substances for treatment. The drug, found in so-called “magic mushrooms,” is a naturally occurring psychedelic compound. Research tracking the effects of the psychedelic drug has found that it has the potential to provide long-term relief for mental health struggles such as anxiety and depression, especially in those receiving palliative care due to a terminal diagnosis. <https://bit.ly/30wmOhf>

N.B. Selected articles on psychedelics for psychological and existential distress in PC noted in this issue of Media Watch.

U.S.A.

Hospice and palliative care providers absorb lessons of COVID-19 to drive change

HOSPICE NEWS | Online – 15 October 2020 – The rapid spread of Coronavirus jolted the nation’s healthcare systems, illuminating breakdowns and deficiencies in the delivery of acute, serious illness and end-of-life care. With millions of Americans falling ill to the virus and thousands dying, a heightened focus has fallen on hospice and palliative care (PC) as providers seek to learn from the COVID-19 experience and grasp the long-term impacts. “Amidst the crises that we’re all living through, we now have new clarity about where we’ve been and where we are now that can inform where we’re going,” said Ira Byock MD, founder and chief medical officer of the Institute for Human Caring during a speech at the National Hospice & Palliative Care Organization Interdisciplinary Care conference. “I have kind of gotten a sense of two alternate futures: one bright one in which we are living examples of the values and vision of the founders of this field; and, the other not so bright in which we progressively shrivel into a husk of that vision, becoming a transactional, commodified version of what founders of hospice and PC had hoped to build.” Dr. Byock went on to say: “We ... need to ask ourselves if we are really

communicating effectively, and does that communication enhance the likelihood of people asking for or accepting the services that we want to offer. Avoiding the words ‘death,’ ‘dying,’ ‘suffering’ and ‘hospice care’ return us to acting out of fear of being misunderstood, fear of being rejected by patients, fear of not being able to serve patients who need and would benefit from our services. Those are all legitimate concerns that we really need to address in creative ways.” <https://bit.ly/3lRzDur>

Specialist Publications

‘End-of-life issues in U.S. child life specialist programs: 2009-2019’ (p.7), in *Child & Youth Care Forum*.

‘Family and friend perceptions of quality of end-of-life care in Medicare Advantage versus traditional Medicare’ (p.8), in *JAMA Open Network*.

‘Factors associate with the adoption and closure of hospital palliative care programs in the U.S.’ (p.9), in *Journal of Palliative Medicine*.



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

A new study suggests that people receiving end-of-life care might be happier than we expect

NEW ZEALAND | *Marie Curie Talkabout* – 14 October 2020 – Picture someone living in a hospice knowing they only have weeks to live. Chances are the word 'happy' isn't one you'd pick out to describe them. But a new study suggests that people receiving palliative care might be more content than we imagine.¹ The study ... found that patients receiving end-of-life (EoL) care were generally happy with their lives, with many finding a new appreciation for the simple things in life. The participants, patients in a hospice in New Zealand, urged young people to avoid focusing on material things and the Internet and instead turn to social connection and the natural world if they want to find happiness. When asked about happiness, the patients often talked about the small, simple, and fleeting occurrences that brought them joy. For some this focus on the simple things may have been a way of managing uncertainty about what the future might hold. Receiving a terminal diagnosis can of course change your outlook on life. And as some

participants revealed, it can also change how happy you feel. Whilst the participants weren't necessarily happier than before, the authors suggest their happiness had changed, and they were able to take great satisfaction from things they would have previously taken for granted. This isn't the first study to suggest that death may not be as frightening for people approaching it as we imagine. A 2017 study compared the experience of people at the EoL with people imagining they were dying soon.² It found that those facing imminent death were more positive than those imagining it, and those facing death became more positive as death approached. <https://bit.ly/342dhAs>

Specialist Publications

'Forgoing life-sustaining treatment: A comparative analysis of regulations in Japan, Korea, Taiwan, and England' (p.4), in *BMC Medical Ethics*.

1. 'Happiness at the end of life: A qualitative study,' *American Journal of Palliative Medicine*, published online 14 July 2020. **Abstract (w. list of references):** <https://bit.ly/2SXO4AM>
2. 'Dying is unexpectedly positive,' *Psychological Science*, published online 1 June 2017. [Noted in Media Watch 5 June 2017 (#515, p.2)] **Full text:** <https://bit.ly/2Hbp32w>

End of life and palliative care: Policy catalysis workshop

U.K. | Academy of Medical Sciences – 14 October 2020 – This report summarises the discussions from a workshop the Academy convened before the COVID-19 pandemic was declared. However even then it was clear that with the U.K.'s ageing population and growing numbers of people living with multiple long-term diseases, the U.K. is going to be facing a rise in people dying in the coming years. This wider context sits alongside a need for open discussion about the limits of medicine, the appropriateness of individual treatments, and the need to focus on each person and what actually matters to them at the end of life – not just what's the matter with them. The current COVID-19 pandemic can only make these conversations more urgent. **Download/view at:** <https://bit.ly/3IOqYZC>

Hospice leaders concerned people with end-of-life care needs could miss essential support as second COVID-19 wave hits says Hospice UK

U.K. | Hospice UK – 14 October 2020 – A Hospice UK survey with 118 hospice leaders revealed: more than two fifths (44%) estimate they will have to reduce the volume of services they provide to people with palliative and EoLC needs, compared to the previous financial year due to the impact of COVID-19; almost a third (32%) believe that reduction will be up to a quarter of services provided; one in ten (14%) think it will be a reduction of up to a third of their services;

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'Paying for end-of-life care in the U.K.' (p.9), in *Mathematical Gazette*.

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three quarters (74%) of those offering day services estimate there will be a reduction in the volume of these services in 2020-2021 compared to the previous year due to the impact of COVID-19; half (50%) believe they may have to reduce day services by up to a third or more compared to last year; 42% estimate the reduction to be up to a half; two thirds (66%) report an increase in referrals for community-based services since the start of the COVID-19 crisis; nearly a quarter (24%) report an increase of up to a third; more than one in ten (14%) have seen referrals increase by up to half; 93% are concerned without further resource people with palliative and EoLC needs could miss out on the support they require; and, 58% are very concerned without further resource people with palliative and EoLC needs could miss out on the support they require. <https://bit.ly/2lrjfCq>

Global Atlas of Palliative Care (2nd edition)

WORLDWIDE HOSPICE PALLIATIVE CARE ALLIANCE | Online – 13 October 2020 – The atlas is a source of essential information on the status of palliative care (PC) worldwide. This second edition of the Global Atlas reveals some of the changes that have occurred since the first edition was published in 2014. For instance, there is now a better idea of how many people need PC worldwide. In the 1st edition a conservative estimate of 40 million has now been more accurately estimated as over 56.8 million, including 25.7 million in the last year of life. **Download/view at:** <https://bit.ly/370atWq>

Noted in Media Watch 5 October 2020 (#686, p.7):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 September 2020 – ‘**Estimating the number of patients receiving specialized palliative care globally in 2017.**’ Significant disparities in palliative care (PC) access exist both by region and income group. The European and Pan-American regions had most while the Eastern Mediterranean, Southeast Asian, and African regions had least. Much more needs to be done to develop and deliver PC in low and middle-income countries (LMICs) where 80% of the need for PC exists. With about 70% of operating PC services in high income countries and only 30% in LMICs, a major effort to develop PC in these settings is urgently needed. If every country had a PC registry, we would have more accurate numbers... **Full text:** <https://bit.ly/3l4f2CX>

Coronavirus in Scotland: Hospices lose half of donations

U.K. (Scotland) | *The Times* (Glasgow) – 12 October 2020 – Hospices in Scotland are facing a multi-million pound fundraising crisis as donors switch their support to National Health Service (NHS) charities. Vital hospice services for the dying and bereaved get two thirds of their funding from charity events and donations. The 16 hospices in Scotland need to raise more than £4.5 million a month. They have seen their fundraising income plummet by about 50% since lockdown began in March. Mass participation events were cancelled, corporate fundraising reduced, charity shops had to close and collections at funerals have been badly affected. However, fundraising managers believe hospices have also lost out because people have given more to [the] NHS Charities Together, formerly Association for NHS Charities, which had not previously been a competitor. <https://bit.ly/3dkwCj9>

Specialist Publications

Forgoing life-sustaining treatment: A comparative analysis of regulations in Japan, Korea, Taiwan, and England

BMC MEDICAL ETHICS | Online – 16 October 2020 – This study compared regulatory frameworks governing forgoing life-sustaining treatment (LST) in Japan, Korea, Taiwan and England, and presented five important legal and philosophical points: 1) The importance of defining the terminal stage and associated criteria for clinical judgment; 2) The importance of discussions on withdrawing LST in persistent vegetative state or motor neurone disease patients who are not terminal; 3) The importance of (re)considering any moral and legal differences between withholding and withdrawing treatments (this is disputed particularly in Asian countries); 4) The importance of ascertaining the family’s role in end-of-life (EoL) decision-making; and, 5) The importance of devising ways to deal with incompetent patients who lack family or advance directives. Focusing on these five points will be important for the establishment of better EoL regulatory frameworks for these four countries and others. **Full text:** <https://bit.ly/31hZTpV>

A mixed-method evaluation of a volunteer navigation intervention for older persons living with chronic illness (Nav-CARE): Findings from a knowledge translation study

BMC PALLIATIVE CARE | Online – 15 October 2020 – This study contributes to a growing body of evidence on how innovative volunteer models can improve care for older persons living at home with chronic illness. Building upon a palliative approach to care, this volunteer-led navigation intervention (Nav-CARE) has the potential to improve social support, access to low-cost resources, healthcare social negotiation and engagement of older persons living at home with advancing chronic illness. Volunteers provided physical and emotional respite for family. Volunteers were well-prepared for, and satisfied in, the Nav-CARE role as long as they were matched with older persons in a timely manner. Further, research needs to be done in developing volunteer-sensitive outcomes so that volunteer contributions can be documented more robustly. The study authors are in the process of scaling out the Nav-CARE intervention to additional sites across Canada to build a more robust understanding of its potential impact. **Full text:** <https://bit.ly/3525lc9>

Noted in Media Watch 10 October 2020 (#687, p.5):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 October 2020 – ‘**A feasibility study of a volunteer navigation program in the palliative context.**’ Older persons with serious illnesses living in rural communities often live with heavy symptom burden and poor quality of life with limited access to resources. Nav-CARE (Navigation: Connecting Accessing Resourcing & 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. 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>

Digital telemedicine interventions for patients with multimorbidity: A systematic review and meta-analysis

BMJ OPEN | Online – 13 October 2020 – The authors’ findings suggest that current evidence for the use of digital telemedicine in multimorbidity is limited and interventions have rarely been evaluated in a systematic fashion. In spite of the considerable role digital telemedicine has taken in public and professional debates in healthcare over the last 15 years, the implementation of digital telemedicine interventions for patients with multimorbidity cannot be recommended because of the weak evidence. Where health services are implementing, it seems sensible to integrate interventions with usual care and adapt them to the local context to not inappropriately divert resources from alternative, non-digital approaches. After implementation, continuous evaluation will help improve practice and also add to the still small evidence base for digital telemedicine for multimorbidity. It is important to ensure interventions are implemented with relevant outcome parameters, determined ideally by taking into account the preferences of patients and healthcare providers and in the best interest of society and the overall health systems and not just as assumed progressive prestige projects. Future high-quality interventional research is needed that includes longer periods of follow-up and should investigate which components of telemedicine are most effective and how usual care, in and across sectors, can best be integrated avoid inappropriately diverting resources from alternative, non-digital approaches. **Full text:** <https://bit.ly/2SViWBO>

Related:

- *BMC PALLIATIVE CARE* | Online – 14 October 2020 – ‘**Patients’ experiences of eHealth in palliative care: An integrative review.**’ This review focused on patients’ experiences of eHealth in palliative care (PC) and, accordingly, it is challenging to state recommendations when considering implementation of eHealth technologies in PC. More robust studies with an element of randomization in accordance with the Medical Research Council guidelines, including evaluation of minimally clinically important differences, are called for to follow up feasibility and acceptability studies. With a holistic view of patients’ needs and well-being, eHealth may contribute to increased value on several levels (micro, meso, macro) for patients, PC services, and healthcare systems. **Full text:** <https://bit.ly/3k4iSM1>

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- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 October 2020 – ‘**Human connection and technology connectivity: A systematic review of available telehealth survey instruments.**’ Twelve telehealth communication assessment instruments were identified... Three inquired only into modality, four queried communication, and five studied both modality and communication experience. Existing instruments are unidirectional in exploring patient or family experience with two inclusive of provider perspectives. Participant demographics are notably under-reported in telehealth experience studies with a frank lack of diversity in ethnic/racial, geographic, age, educational, and income representativeness in current telehealth survey instrument respondents. **Abstract (w. list of references):** <https://bit.ly/316ZJBF>

Noted in Media Watch 16 December 2019 (#644, p.7):

- *BMC PALLIATIVE CARE* | Online – 13 December 2019 – ‘**Telehealth in palliative care is being described but not evaluated: A systematic review.**’ This review demonstrates that a variety palliative care (PC) telehealth initiatives continue to be described in the published literature. Since a 2010 review there particularly appears to have been an increase in the number of home tele-monitoring interventions... Despite the description of telehealth development and implementation, there remains a lack of robust study design and evaluation of these interventions meaning that clear conclusions around the benefit of telehealth in PC cannot be drawn; there is insufficient high quality evidence to comment on any influence on access to emergency or unscheduled care. **Full text:** <http://bit.ly/2PJKJmT>

N.B. The role of telemedicine in end-of-life and PC noted in Media Watch 10 August 2020 (#678, pp.5-6) and 15 June 2020 (#670, pp.8-9).

How to communicate with families living in complete isolation

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 15 October 2020 – The communication typical of the globalised world, during an overwhelming pandemic, can give way to an experience of silent solitude: the loneliness of the patient and anguished isolation of family members and of healthcare professionals within their hospitals. A phone call, a video call, an email, a written story try to replace the physical contact that the isolation prohibits: communicating with the family allows people to create a listening space where worries, anguish of death and fears are collected for themselves and their loved ones far away, and in which they try to build trust and hope. It is crucial to establish contact with family members. A well-conducted phone call by the doctor on the clinical conditions, in a daily communication round, becomes a tool to care for those who cannot personally see their loved one, who suffer the anxiety of not having direct information and, often, ease the sense of guilt linked to “the feeling of abandoning his/her own loved one.” We inform, reassure, collect tears and together we build the hope for containing and eventually overcoming a psychological trauma that will leave its marks in future years. Otherwise we end up accompanying the pain of a death without closeness and with no direct participation, but at least not loneliness. **Full text:** <https://bit.ly/2H81asX>

Aims of communication with family members	Topics discussed in this position paper	Statements on communication with families
A To provide understandable information about the disease and treatment options	A1 Relational aptitude	S1 Relatives must be given clinical information at least once a day, and more often in case of any substantial and unexpected worsening in the patient's condition. S2 A doctor who knows the patient directly must be the person to give the relatives clinical information.
	A2 Preparation	
	A3 Justice	
B To obtain information on expectations and choices	B1 Confidentiality	S3 Any healthworker who feels it is too much of a burden at that specific time is not obliged to give the relatives information. S4 The staff's mental and emotional wellbeing must be taken into consideration and protected.
	C To show collaboration	C1 Health workers' wellbeing
C2 Internal communication		
D To allow relatives to express their emotions	D1 Grief	S7 Information must be given in an appropriate, unequivocal, truthful way. S8 Attempts to reconstruct the patient's preferences should be carried out together with the family.
	E To prevent misunderstandings and conflicts with the care team	E1 Management of different tasks
E2 Truth, coherence, gradualness		
E3 Legal aspects		

End-of-life issues in U.S. child life specialist programs: 2009-2019

CHILD & YOUTH CARE FORUM | Online – 6 October 2020 – Child life specialists (CLS) play a crucial role with children and their families when the child has a life-threatening illness and is hospitalized by trying to establish some degree of normalcy in a situation void of such. Programs designed to train CLS have expanded over the last 10 years. The authors surveyed the 48 child life academic programs in the U.S. in 2019 and compared these findings with the earlier survey in 2009. They also analyzed the websites of all 48 programs to obtain a better understanding of current death and dying offerings in U.S. child life programs. All child life programs now include content on death, dying, and bereavement. Child life programs continue to emphasize end-of-life issues, with CLS being the primary deliverers of such information. Communication with patients with life-threatening illnesses, communication with family members of such patients, and grief and bereavement were the three most covered topics in both 2009 and 2019. **Abstract (w. list of references):** <https://bit.ly/2GSa10f>

Noted in Media Watch 17 June 2019 (#618, p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 10 June 2019 – ‘**Role of child life specialists in pediatric palliative care.**’ An important member of the pediatric team or specialist palliative care providing care to the child and family is the child life specialist (CLS). The CLSs apply their training in child development to reduce distress and potentially gain insights into the child’s thoughts. They may help children and their families navigate through the challenging and emotionally draining process of hospitalization, prepare children for upcoming procedures, and assist them in working through feelings about past and impending experiences. Their goal is to provide emotional and spiritual support in a developmentally appropriate way, educate, and advocate... **Full text:** <http://bit.ly/2KJlxMf>

Hospice in Israel

Challenges in home care at the end stage of dementia: Hospice units vs. home care units. A qualitative study

DEATH STUDIES | Online – 10 October 2020 – Home hospice units specializing in palliative end-of-life care (EoLC) are uncommon despite the theoretical benefit for people with end stage dementia (PWESD). The authors described the challenges of caring for PWESD and their families using 24 semi-structured in-depth interviews with professional staff members from two care settings – home hospice units and home care units – in Israel. Staff described EoLC for PWESD in four sub-themes: 1) Dementia as an end-stage disease; 2) Appropriateness of palliative care for PWESD; 3) A family member at the center of care; and, 4) “Dying-in-place” versus hospitalization. **Abstract:** <https://bit.ly/2SKesOv>

Noted in Media Watch 31 August 2020 (#681, p.8):

- *ISRAEL JOURNAL OF HEALTH POLICY RESEARCH* | Online – 24 August 2020 – ‘**At the crossroads of religion and palliative care in patients with dementia.**’ A recent pilot study by Sternberg *et al* of 20 patients with advanced dementia in Israel found that home hospice care significantly reduced distressing symptoms, caregiver burden and hospitalization and teaches us important lessons about some of the essential elements to providing excellent palliative care (PC) at home, including the 24/7 availability of healthcare providers outside of the emergency department.¹ In light of specific religious practices, PC should strive to incorporate a patient’s specific religious observance as part of high-quality end-of-life care. **Full text:** <https://bit.ly/34wZAKk>

1. ‘Home hospice for older people with advanced dementia: A pilot project,’ *Israel Journal of Health Policy Research*, published online 6 May 2019. **Full text:** <https://bit.ly/32s2j5n>

N.B. Additional articles on hospice and palliative and EoLC for people living with dementia noted in Media Watch 10 August 2020 (#678, pp.13-14).

End-of-life care in the U.S.

Family and friend perceptions of quality of end-of-life care in Medicare Advantage versus traditional Medicare

JAMA OPEN NETWORK | Online – 13 October 2020 – Does the quality of care (QoC) at the end of life (EoL) as reported by bereaved family and friends differ for people enrolled in Medicare Advantage (MA) versus traditional Medicare at the EoL? The findings of this cross-sectional study suggest that patients at the EoL, a population with serious illness and high needs, experience lower QoC in MA as perceived by family and close friends. This should draw the attention of Medicare, as well as state Medicaid programs, which are highly invested in the care of this population. Medicare and states could systematically assess quality of EoL care, including through direct reports from family and close friends, and carefully monitor the quality of hospice care under a potential future hospice carve-in to protect these individuals and their caregivers. While MA plans may increasingly appeal to older adults because of these plans' lower costs and expanded benefits, MA plans must also offer equal or improved QoC to those in the last days of life. **Full text:** <https://bit.ly/3iTrmUR>

Association of receipt of palliative care interventions with healthcare use, quality of life, and symptom burden among adults with chronic non-cancer illness: A systematic review and meta-analysis

JOURNAL OF AMERICAN MEDICAL ASSOCIATION, 2020;324(14):1439-1450. In this systematic review and meta-analysis of 28 randomized clinical trials of patients with primarily non-cancer illness, receipt of PC interventions, compared with usual care, was statistically significantly associated with less acute healthcare use and modestly lower symptom burden, but there was no significant difference in quality of life. Among patients with primarily non-cancer illness, receipt of PC interventions was associated with lower acute healthcare use and modestly lower symptom burden, although analyses for some outcomes were based predominantly on studies of patients with heart failure, which may limit the generalizability of these findings to other chronic illnesses. **Abstract:** <https://bit.ly/34SAkNp>

Noted in Media Watch 13 July 2020 (#674, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 6 July 2020 – ‘**Association between palliative care and healthcare outcomes among adults with terminal non-cancer illness: Population based matched cohort study.**’ This study supports the role palliative care (PC) has in providing high value end-of-life (EoL) care to people dying from cancer and most non-cancer illness. The authors found PC might reduce healthcare use and potentially burdensome interventions near EoL. They found an association between PC and an increased odds of dying at home, which is where most people would prefer to die and a recognised indicator of high quality EoL care. Their findings are consistent with previous literature on the association between home-based PC and healthcare use outcomes... **Full text:** <https://bit.ly/2O2Ds0Q>

Hospice response to COVID-19: Promoting sustainable inclusion strategies for racial and ethnic minorities

JOURNAL OF GERONTOLOGICAL SOCIAL WORK | Online – 11 October 2020 – There is a disproportionate burden of illness and death among racial/ethnic minorities related to COVID-19. The importance of reaching groups suffering the most with resources such as advance directive guidance, telehealth, and culturally sensitive education materials is vital to providing quality, inclusive care. A crisis presents an opportunity to unite and problem-solve to help avoid the dire consequences facing inaction. In this way, inclusive responses by hospices, social workers, other community partners during the COVID-19 pandemic can help reach and alleviate the pain of those groups most afflicted. The authors offer hospice inclusion strategies that align with general pandemic response trends that may lead to greater hospice inclusion beyond this public health emergency. **Abstract:** <https://bit.ly/2GP0EzU>

N.B. Selected articles on disparities in the provision and delivery of hospice and palliative care for racial/ethnic minorities in the U.S. noted in Media Watch 31 August 2020 (#681, p.3).

Factors associate with the adoption and closure of hospital palliative care programs in the U.S.

JOURNAL OF PALLIATIVE MEDICINE | Online – 15 October 2020 – In the U.S., the percentage of hospitals over 50 beds with palliative care (PC) programs has risen substantially from 7% of hospitals in 2001 to 72% in 2017. Yet the dynamic nature of program adoption and closure over time is not known. The authors examined the rate of PC program adoption and closure and associated hospital and geographic characteristics in a national sample of U.S. hospitals. By 2017, 34.9% (812/2327) of the hospitals without PC in 2009 had adopted PC programs, and 15.0% (205/1369) of the hospitals with programs had closed them. In multivariable models, hospitals in metropolitan areas, non-profit and public hospitals (compared to for-profit hospitals), and those with residency training approval by the Accreditation Council for Graduate Medical Education were significantly more likely to adopt and significantly less likely to close PC programs during the study period. This study indicates that PC is not equitably adopted nor sustained by hospitals in the U.S. Federal and state interventions may be required to ensure that high-quality care is available to our nation's sickest patients. **Abstract:** <https://bit.ly/352r8pz>

Paying for end-of-life care in the U.K.

MATHEMATICAL GAZETTE, 2020;104(561):495-506. To live to a ripe old age, untroubled by health problems, physical or mental, is an almost universal aspiration. But most people are not so lucky and will likely be in care homes for their final years, with varying levels of disease, disability and dementia. Kinley *et al* maintain that over a fifth of the population of developed countries die in care homes. Moreover, the financial cost of this end-of-life care ... can be daunting and require much planning. It was reported in 2017 that, in the U.K., care home costs are rising up to twice as fast as inflation. Consequently the question arises about the long term affordability of such care to those having to fund it, a question that ever more people both nationally and globally are having to confront. **Abstract (w. list of references):** <https://bit.ly/37efafx>

Gender and palliative care: A call to arms

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 15 October 2020 – There has been a systematic and largely unconscious neglect of gender in palliative care (PC) research, practice and policy. This is despite significant, although previously uncollated, evidence that gender influences almost all aspects of end-of-life (EoL) preferences, experiences and care. The social situations of women, transgender people and men often differ from one another while also intersecting in complex ways with sex differences rooted in biology. If PC is to meet its aspiration of providing universal benefit, it urgently needs to address a range of gender inequalities currently (re)produced at the level of the laboratory all the way through to government departments. The authors spotlight specific instances where gender inequalities have been documented, for example, regarding EoL caregiving, EoL intervention and PC access and benefit. They highlight how gender inequalities intersect with other social determinants of health including ethnicity and economic status to exacerbate situations of marginality. **Full text:** <https://bit.ly/2SZG961>

Tools to help healthcare professionals recognize palliative care needs in patients with advanced heart failure: A systematic review

PALLIATIVE MEDICINE | Online – 15 October 2020 – The delivery of palliative care (PC) interventions is not widely integrated in chronic heart failure (HF) care as the recognition of PC needs is perceived as difficult. Tools may facilitate healthcare professionals (HCPs) to identify patients with PC needs in advanced chronic HF. In this systematic review, nineteen studies described a total of seven tools. The tools varied in purpose, intended user and properties. The tools have been validated to a limited extent in the context of chronic HF and PC. Different HCPs applied the tools in various settings at different moments of the care process. Guidance and instruction about how to apply the tool revealed to be relevant but may be not enough for uptake. Spiritual care needs were perceived as difficult to assess. Seven tools were identified which showed different and limited levels of validity in the context of PC and chronic HF. **Full text:** <https://bit.ly/3j1HaFb>

N.B. Additional articles on meeting the PC needs of patients living with HF noted in Media Watch 14 September 2020 (#683, p.8).

Prevalence of burnout in healthcare professionals providing palliative care and the effect of interventions to reduce symptoms: A systematic literature review

PALLIATIVE MEDICINE | Online – 15 October 2020 – In recent years there has been increasing attention for the prevalence and prevention of burnout among healthcare professionals (HCPs). There is unclarity about prevalence of burnout in HCPs providing palliative care (PC) and little is known about effective interventions in this area. In total 59 studies were included in this review. Burnout among HCPs providing PC ranged from 3% to 66%. No major differences in prevalence were found between nurses and physicians. HCPs providing PC in general settings experience more symptoms of burnout than those in specialised PC settings. Ten studies reported on the effects of interventions aimed at preventing burnout. Reduction of one or more symptoms of burnout after the intervention was reported in six studies which were aimed at learning meditation, improving communication skills, peer-coaching and art-therapy based supervision. The range of burnout among HCPs providing PC varies widely. Interventions based on meditation, communication training, peer-coaching and art-therapy based supervision have positive effects but long-term outcomes are not known yet. **Abstract (w. list of references):** <https://bit.ly/353qKau>

N.B. Selected articles on burn-out, compassion fatigue, and the well-being and resilience practices in the hospice and PC workforce noted in Media Watch 31 August 2020 (#681, p.8).

The pitfalls of utilizing “goals-of-care” as a clinical buzz phrase: A case study and proposed solution

PALLIATIVE MEDICINE REPORTS, 2020;1(1):216-220. Assistance with discussing goals-of-care is one of the most common reasons clinicians seek out palliative care consultation. In practice though, the phrase “goals-of-care” is often utilized as a buzz phrase that lacks a shared understanding of its clinical relevance. The authors present a case example in which breakdowns in communication occurred between a patient and clinicians due to misunderstandings of the meaning of the phrase “goals-of-care.” Subsequently, they review the literature to propose a unified definition of “goals-of-care” in hopes to minimize differences in what this phrase implies in clinical practice. The authors also seek to introduce a standardized process for establishing goals-of-care that may offer a more reliable and measurable method to promote goal-concordant care. **Full text:** <https://bit.ly/3jPM49G>

Palliative care in Norway

Challenges and learning needs for providers of advanced cancer care: Focus group interviews with physicians and nurses

PALLIATIVE MEDICINE REPORTS, 2020;1(1): 208-215. Implementation of integrated oncology and palliative care (PC) improves patient outcomes, but may represent a demanding task for healthcare providers (HCPs). The discussions in the interviews [with residents in oncology, oncologists, nurses, and PC physicians concerned three broad themes: 1) An emphasis on patients' best interest, perceived as hindered by two sets of barriers; 2) Unsatisfactory organizational conditions, such as time pressure, lack of referral routines; and, 3) Few arenas for interdisciplinary collaboration was perceived as one barrier. The other barrier was related to the appraisal of other HCPs' clinical practices. Participating HCPs expressed in general a positive self-view, but were more critical of other HCPs. Currently, implementation of measures to improve care for patients with advanced cancer appears to be challenging

due to cultural and organizational factors, and how HCPs perceive themselves and other HCPs. HCPs' perception of challenges in patient care as not related to themselves ... might be an essential obstacle. Interventions targeting both HCP-related and organizational factors are needed. **Full text:** <https://bit.ly/3iMFT4F>

Extracts from *Palliative Medicine Reports* article

Early integration of oncology and PC has, however, proved challenging to implement due to several barriers. These barriers include doubts about the usefulness and importance of PC among oncologists, insufficient collaboration between various healthcare professions, non-involvement of patients in decisions of care, the misunderstanding of PC as EoL care only, and insufficient organizational factors.

Media Watch: Access on Online

International



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

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

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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



CSPCP Canadian Society of
Palliative Care Physicians
SCMSP Société canadienne des
médecins de soins palliatifs

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>



Palliative Care Network

Palliative Care for Everyone, Everywhere

Closing the Gap Between
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Media Watch: Behind the Scenes
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Media Watch: Editorial Practice

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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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