

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.

14 September 2020 Edition | Issue #683



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To increase the acceptability of palliative care (PC) for both patients and clinicians, as well as to delink it from death, PC practices around the country are substituting the name “palliative care” with “supportive care.”

'In pandemic era, the term palliative care is even more scary for some. So specialists want to rename it' (p.3), in *The Washington Post*.

Canada

Canada Post set recognizes modern medical innovators

LINN'S STAMP NEWS | Online – 10 September 2020 – Canada Post honors the country's medical trailblazers with five non-denominated permanent-rate stamps. The designs show six of the country's cutting-edge physicians and researchers including palliative care (PC) physician Balfour Mount. Dr. Mount is credited with coining the term “palliative care” and advocating for a compassionate whole-person approach to caring for individuals suffering from a life-threatening illness. In 1975, he founded the world's first comprehensive PC service based in a teaching hospital at the Royal Victoria Hospital in Montreal, Quebec. <https://bit.ly/33i0liM>



Province announces funding for palliative care in Alberta

ALBERTA | *The Lethbridge News* – 9 September 2020 – The Government of Alberta has announced the “first step” in a \$20-million commitment to improving palliative care (PC). \$5 million will be given to the Covenant Health Palliative Institute to increase access to palliative and end-of-life (EoL) services as well as to promote advance care planning. \$1 million will be provided to the Alberta Hospice Palliative Care Association to establish in-person and online support groups, develop Alberta's first telephone grief support line, and expand workshops on PC. As well, co-payments for EoL drugs are being eliminated. The government estimates that every year, about 2,700 Albertans choose to die at home or in a hospice. In a hospital, these drugs would be covered in hospitals, but patients would have to pay out-of-pocket elsewhere. <https://bit.ly/3bJmwHU>



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Life, Death & Dignity: A three-part community discussion series

BRITISH COLUMBIA | Victoria Hospice – Accessed 6 September 2020 – This initiative was a collaboration involving Victoria Hospice, This is Table Talk, and the Victoria Immigrant and Refugee Society and Centre. Due to COVID-19 related restrictions, the series was hosted virtually through Zoom and was attended by 45 community members and ten Victoria Hospice staff members. Overall, the series was successful in creating a space where community members felt safe to talk about death and dying, their experiences and their needs, and barriers regarding end-of-life care. **Download/view final report at:** <https://bit.ly/35cgl4c>

U.S.A.

Hospitals partner with nursing homes to prevent and fight outbreaks

ASSOCIATION OF AMERICAN MEDICAL COLLEGES | Online – 8 September 2020 – University Hospitals Cleveland Medical Center is one of several academic medical centers across the U.S. that have developed partnerships with nursing homes and other long-term care facilities in their communities to lend their resources and expertise to mitigate the impact of COVID-19 in these settings where the virus is disproportionately serious or fatal. Academic medical centers – as home institutions for experts in infection prevention and control, specialists on top of cutting edge research, and leaders in community and public health – are uniquely positioned to extend these resources to congregate care settings in crisis... University of Washington (UW) Medicine, like many academic medical centers across the country, has formal relationships with skilled nursing facilities in the community to improve the transition for patients between hospitals and these facilities. A team from UW Medicine used the existing relationships with 16 facilities in its network to develop and implement a three-phase approach to supporting facilities' responses to COVID-19. The team's involvement ranged from help with planning before any infections entered a building to deploying an emergency "drop team" – made up of volunteer clinicians, nurse practitioners, and an infectious disease expert – within 24 hours to a facility that was becoming overwhelmed by an outbreak. <https://bit.ly/2ZmXl9k>

Rethinking palliative care

In the pre-pandemic world, when a resident in a nursing home was nearing the end of life, hospice care workers would come into the facility to provide support. But with the dangers of COVID-19, even as more residents were becoming sick and dying, most facilities no longer allowed outside providers to come in. "So many residents were infected and didn't want to go to the hospital," says Nina O'Connor, MD, chief of palliative care (PC) at the University of Pennsylvania Health System (Penn Medicine). This meant that O'Connor and other PC experts had to rethink how to provide care and support to residents and their families. As part of a larger collaboration with the public health department in Philadelphia, Penn Medicine created a virtual PC support program that connected nursing home staff, residents, and families to resources.¹ This included making medical center experts available to help with advance care planning, symptom management, medication recommendations, speaking with family members about treatment options, and making connections to social workers and chaplains to help residents and grieving families.

1. Palliative care pandemic support for long-term care,' *Journal of Palliative Medicine*, letter to the editor published online 9 June 2020. <https://bit.ly/2ZpS0xY>

In pandemic era, the term palliative care is even more scary for some. So specialists want to rename it.

THE WASHINGTON POST | Online – 7 September 2020 – Palliative care (PC) has an image problem. It's a medical specialty that focuses on providing relief from the symptoms and stress of a serious illness to improve the quality of life for both patient and caregivers. But while the specialty's goal is to help all patients with a serious, potentially life-threatening illness, PC specialists are almost always involved with patients approaching the end of life. The result is that the very phrase "palliative care" has become frightening to many people with critical illnesses and their families, wrongly raising the idea that they are being sent to specialists who will help them die. Now a growing movement is advocating to rename PC so that patients – and doctors – won't fear using it. A recently published research study analyzing the general public's perception of PC among more than 5,000 older Americans revealed that over 70% of participants did not even know what PC was.¹ Of those who are aware of PC, the

same study shows almost two-thirds think it is the same as hospice, which is a service delivered at home or in a facility for someone with an expected survival of no more than six months. Most physicians are likely to call PC specialists primarily when death is imminent – many worry that calling in a PC consultation will increase anxiety and fear among patients. <https://wapo.st/3bydFJ7>

Extract from *The Washington Post* article

To increase the acceptability of PC for both patients and clinicians, as well as to delink it from death, PC practices around the country are substituting the name "palliative care" with "supportive care."

N.B. Selected articles on terminology in the context of living with a life-threatening or a life-limiting illness and end-of-life care noted in Media Watch 4 March 2019 (#604, pp.8-9).

1. 'Public perceptions of advance care planning, palliative care, and hospice: A scoping review,' *Journal of Palliative Medicine*, published online 2 July 2020. [Noted in Media Watch 6 July 2020 (#673, p.11)] **Abstract:** <https://bit.ly/3gl24yf>

Noted in Media Watch 29 June 2020 (#672, p.5):

- *BMC PALLIATIVE CARE* | Online – 22 June 2020 – '**Palliative care in its own discourse: A focused ethnography of professional messaging in palliative care.**' Despite 50 years of modern palliative care (PC), a misunderstanding of its purpose persists. The original message that PC is focused on total care, helping to live until the person dies, is being replaced and linked to feelings of fear, anxiety and death, instead of compassion, support or appropriate care. Society is still afraid to speak its name, and specialized units are identified as "places of death" as opposed to "places of life" meant to treat suffering. It is imperative to identify what message PC professionals are relaying ... and how that message may condition understandings of the right to access PC. **Full text:** <https://bit.ly/2YnJ8sm>

Noted in Media Watch 16 March 2020 (#657, p.9):

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 10 March 2020 – '**Lack of awareness and common misconceptions about palliative care among U.S. adults: Insights from a national survey.**' Despite recent growth in palliative care (PC) programs PC remains underutilized. Studies suggest that patients and providers commonly associate PC with end of life, often leading to misconceptions and late referrals. PC knowledge was self-reported in response to: "How would you describe your level of knowledge about PC?" Level of misconceptions was based on a series of factual and attitudinal statements about PC. Among U.S. adults, 28.8% report knowing about PC, but only 12.6% report knowing what PC is and hold no misconceptions. **Abstract (w. list of references):** <http://bit.ly/2TLOtaJ>

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Would the *Washington Post* article be of interest to a colleague?

Noted in Media Watch 7 October 2019 (#634, p.13):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 1 October 2019 – ‘**Palliative care knowledge, information sources, and beliefs: Results of a national survey of adults in the U.S.**’ Despite its established benefits, palliative care (PC) is not well known among patients and family/caregivers. Approximately 29% of 3,504 respondents knew about PC. Less PC knowledge was associated with lower age, male gender, lower education, and non-internet users. A little over half (55%) of respondents accessed healthcare providers first for PC information, and 80% considered providers the most trusted source of PC information. Data from the survey provide a baseline from which PC education policies and interventions may be measured. **Abstract (w. list of references):** <http://bit.ly/2ppubXV>

International

Care homes as hospices: The problem with long-term care provision towards the end of life in England

U.K. (England) | *British Politics & Policy* – 10 September 2020 – The Coronavirus crisis has exposed clear and deep-rooted inequalities across society. These divisions are particularly stark in the disparities we see in funding and access to end of life (EoL) care. That a large proportion of COVID-19 deaths in England & Wales has come from those living in care homes should thus come as little surprise: over a significant period, there has neither been the attention given, nor the resources allocated, to properly support the oldest and most disabled adults in our society. Compared to people aged over-50 who receive long-term care (LTC), those aged 80+ and those living with severe disability, dementia or the effects of stroke, more often than not live and die in care homes as opposed to other LTC settings such as hospices or at home. Dying from cancer is also provided for under the National Health Service and hospice sectors, but dying in very old age from dementia or chronic conditions is a social care remit, which is mostly subsidised by self-funders. While care homes are the new hospices for many, they also have far fewer resources to deal with EoL care when compared to hospices. <https://bit.ly/35pH0UQ>

Noted in Media Watch 6 July 2020 (#673, p.13):

- *SOCIAL SCIENCE & MEDICINE* | Online – 1 July 2020 – ‘**Care homes as hospices for the prevalent form of dying: An analysis of long-term care provision towards the end of life in England.**’ In the U.K. most people die aged 80+ from disabling, chronic and degenerative diseases, having spent several years in poor health. There is thus continuity between long-term care (LTC) and end of life (EoL) care in old age, but this continuity is poorly understood within policy and almost nothing is known about what determines the modality and intensity of LTC provision in old age towards the EoL. Hospices provide EoL LTC for cancer diagnoses, while care homes provide open-ended and EoL LTC for non-cancer diagnoses, dementia, severe disability, and adults aged 80+. **Abstract:** <https://bit.ly/3f8P5PK>

Specialist Publications

‘**Integration of a palliative approach into heart failure care: A European Society of Cardiology Heart Failure Association position paper**’ (p.8), in *European Journal of Heart Failure*.

‘**Potentially inappropriate treatments at the end of life in nursing home residents: Findings from the PACE cross-sectional study in 6 European countries**’ (p.9), in *Journal of Pain & Symptom Management*.

‘**Nursing education on palliative care across Europe: Results and recommendations from the European Association for Palliative Care (EAPC) Taskforce on preparation for practice in palliative care nursing across the European Union based on an online-survey and country reports**’ (p.10), in *Palliative Medicine*.

More children living with life-shortening conditions

U.K. (Scotland) | *Third Force News* (Edinburgh) – 9 September 2020 – The number of babies, children and young people in Scotland with life-shortening conditions is rising, a new report has revealed.¹ Research for Children’s Hospices Across Scotland (CHAS) found there were more than 16,700 people aged 21 and under with terminal conditions in the country, 2,000 of whom have conditions described as unstable or deteriorating. The report, delivered by Public Health Scotland, revealed that children with a life-shortening condition are 50% more likely to be living in a deprived area than an affluent one. In a bid to ensure more people can access its services, CHAS has launched a new plan to reach every family in Scotland who needs help. Working with the National Health Service, councils, charities and other partners, the charity will concentrate its efforts where they can have the most impact, amongst children who are least stable. <https://bit.ly/3bHYkFW>

1. ‘Children in Scotland Requiring Palliative Care,’ Children’s Hospices Across Scotland, September 2020. Download/view at: <https://bit.ly/3bHZcKI>

Social care staff not given human rights training to deal with COVID-19 impact, finds research

U.K. (England, Scotland & Wales) | *Community Care* – 8 September 2020 – Many social care professionals have not received legal training or information about upholding human rights or using emergency powers during the COVID-19 pandemic, new research suggests. The British Institute of Human Rights, which carried out the research, said the findings were “very concerning” because of the significant changes to law and working practices during the coronavirus crisis. The organisation surveyed 230 health and social care staff, representatives from advocacy groups and charities, and people with care and support needs and their carers, and the research also drew upon the Institute’s work during the pandemic with 950 staff and 400 people using services. Over three-quarters of staff surveyed said they had not received training or information on upholding human rights law and 79% had not in relation to emergency powers under the Coronavirus Act 2020. The act, which was passed at great speed in March before the peak of the

pandemic, allows local authorities to suspend key duties under the Care Act and its equivalent Welsh legislation. <https://bit.ly/2FgKfmC>

Extract from *Community Care* report

The pandemic has “shone a stark spotlight” on the issue of do not resuscitate orders – otherwise known as do not attempt cardiopulmonary resuscitation (DNACPR) orders – with 34% of health and social care staff experiencing pressure to put an order in place without involving the person in the decision. According to Resuscitation Council UK, policies and individual decisions about CPR and DNACPRs must comply with the Human Rights Act 1998. An individual has to be involved in the decision-making process, the decision must be non-discriminatory, and the implementation of an order must not lead to withholding of other elements of treatment. The government has agreed to issue new guidance on DNACPR orders in response to concerns over their use during the pandemic.

N.B. The British Institute of Human Rights reports on the impact of of the Government’s response to the COVID-19 for the human rights of people with care and support needs can be downloaded/vied at: <https://bit.ly/2R8EYQW>

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>

The pandemic is boosting efforts to get the old out of prison

THE ECONOMIST | Online – 7 September 2020 – Globally the number of old people behind bars is increasing at a phenomenal rate. In Britain, the number aged over 60 has jumped by 243% since 2002, to 5,176 in March 2020; they make up 6% of the prison population. Today 20% of Japan's inmates are 60 or older, double the proportion in 2002. The American Civil Liberties Union ... estimates that by 2030 one-third of all inmates in America will be older than 55. They already make up a larger share of the state-prison population than do people aged 18-24. Prisons were built for fit and healthy young men, not people who need handrails in the shower, bed hoists or escorting to the toilet. Old people have more health problems, often chronic, such as dementia, or incurable, like some cancers. Rich countries have started to acknowledge that their prisons now have to be nursing homes and hospices. But prison guards are trained in discipline and security, not nursing. In some cases prisons set up hospices on their grounds. HMP Whatton provides palliative care... Both Britain and America have acknowledged the growing number of elderly inmates and the associated problems. Yet neither country has a national strategy to deal with older offenders. That

means provisions to deal with them are improvised and often depend on the prison – with varying results. <https://econ.st/3bFnFjN>



Prison Hospice: Backgrounder

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

Photo: Lori Waselchuk. Philadelphia, PA

Specialist Publications

The assessment of pain and barriers to pain management: A content analysis from a national sample of hospice psychosocial assessments completed by social workers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 September 2020 – Medicare regulations [in the U.S.] require hospices to complete a psychosocial assessment with content such as patient/family adjustment to illness. Pain barriers such as concerns about addiction, and fatalism are recognized impediments to high quality pain management. National data concerning whether hospice social workers are paying attention to issues related to patient pain is minimal. Addressing this gap, the authors randomly sampled 248 hospices nationally and requested a blank copy of their social work psychosocial assessment and reviewed its pain-related content. A total of 105 hospices (response rate 42.3%) provided an assessment for review. Analyses examined whether pain assessment content was included based on agency characteristics. Of the 105 participating agencies, most were non-profit (60%) and located in the South (30.5%).

Less than half (47.6%) of the agencies included pain assessment content in their assessment. No associations were observed between having pain assessment content and agency characteristics. None of the assessments included content about 3 barriers to pain management: tolerance, overdose, stigma, and fatalism. Few agencies included other barriers to pain management: addic-

Publishing Matters

'Money down the drain: Predatory publishing in the COVID-19 era' (p.12), in *Canadian Journal of Public Health*.

'A qualitative content analysis of watchlists vs safelists: How do they address the issue of predatory publishing?' (p.12), in *Journal of Academic Librarianship*.

Cont.

tion (1%), burden (1%), non-adherence (3.8%), and stoicism (18.1%). Agencies which had pain assessment content mostly included other dimensions of pain: psychological (80%), emotional (74%), and social (78%). Hospice social workers can do more to assess and address pain concerns – especially psychological, social, and emotional dimensions. **Abstract (w. list of references):** <https://bit.ly/33fk48n>

Related:

- *BRITISH JOURNAL OF GENERAL PRACTICE* | Online – 7 September 2020 – ‘**GPs’ decisions about prescribing end-of-life anticipatory medications: A qualitative study.**’ The prescribing of anticipatory medications to provide symptom relief in last days of life care is recommended practice in the U.K., Australia and New Zealand. GPs have a central role in the prescribing of anticipatory medications, but little is known about their decision-making processes and how they discuss these with patients and families. This study found that GPs are keen to prescribe drugs weeks ahead of death even if they are unlikely to be needed. GPs often recall framing anticipatory medications as their clinical recommendation to ensure that the prescription is accepted by patients and their families. **Full text:** <https://bit.ly/3i9SQpR>

Kidney supportive care: An update of the current state of the art of palliative care in chronic kidney disease patients

BRAZILIAN JOURNAL OF NEPHROLOGY | Online – 4 September 2020 – Over the past 20 years there were a great advance in renal palliative care (PC) that came with a better understanding of the basic pathophysiology and management of symptoms in chronic kidney disease (CKD), prognostication tools, and improvement in difficult communication. Besides, with the demographic change all around the world, there is a growing number of patients opting for conservative care without dialysis by their own option or medical recommendation. In addition, dialysis is changing from a disease-centered to person-centered treatment, where a health literate patient choose how, when, and where they desire to do it. Foregoing dialysis seems to be increasing despite dialysis discontinuation still being a conundrum to most nephrologists. Despite the development of PC, there is an enormous gap between theory and practice in nephrology, and the integration of a PC service to the usual renal care is still incipient or non-existent in Brazil. Therefore, one could argue that it is mandatory that scientific societies and governments be involved in creating policies for a sustainable health system by means of education and training in renal PC. **Full text (click on pdf icon for either Portuguese or English language version):** <https://bit.ly/3if0oaK>

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

What do teachers think of death education?

DEATH STUDIES | Online – 11 September 2020 – This study sets out to address a gap in research into teachers’ attitudes and opinions toward death education. To meet this objective, two complementary instruments were designed and validated: the Death Education Attitudes Scale-Teachers (DEAS-T), which showed suitable psychometric values, and the Death Education Questionnaire-Teachers (DEQ-T). The sample comprised 683 teachers from a range of schools. The results show moderately positive attitudes toward death education. Variables such as gender, age, type of teacher, and religious beliefs all influenced results. The findings argue in favor of the inclusion of death in education and teacher training. **Abstract:** <https://bit.ly/2Fw1YGG>

Noted in Media Watch 13 July 2020 (#674, p.6):

- *BEHAVIOURAL SCIENCES* | Online – 7 July 2020 – ‘**Enhancing existential thinking through death education: A qualitative study among high school students.**’ This study confirms the relevance of death education in high schools, highlighting how adolescents can manage issues on death, their fears and doubts. Their texts highlighted how the course contributed to reducing the anxiety linked to these themes, improved the communication between peers and made it more authentic and empathic, providing different alternative perspectives on life and its sense. Indeed, the project offered the occasion to talk about something that is strongly heartfelt but so rarely faced. Students appreciated the opportunity to express their fears, doubts and ideas. **Full text:** <https://bit.ly/2ZdAbCw>

N.B. Selected articles on the topic of dying and death in the school curriculum noted in Media Watch 14 October 2019 (#635, pp.5-6).

Integration of a palliative approach into heart failure care: A European Society of Cardiology Heart Failure Association position paper

EUROPEAN JOURNAL OF HEART FAILURE | Online – 6 September 2020 – Integrating palliative care (PC) into evidence-based heart failure (HF) management remains challenging for many professionals, as it includes the identification of PC needs, symptom control, adjustment of drug and device therapy, advance care planning, family and informal caregiver support, and trying to ensure a “good death.” This new position paper aims to provide day-to-day practical clinical guidance on these topics, supporting the coordinated provision of palliation strategies as goals-of-care fluctuate along the HF disease trajectory. The specific components of PC for symptom alleviation, spiritual and psychosocial support, and the appropriate modification of guideline-directed treatment protocols, including drug deprescription and device deactivation, are described for the chronic, crisis and terminal phases of HF. **Abstract:** <https://bit.ly/2R4dcVr>

Related:

- *CIRCULATION: HEART FAILURE* | Online – 9 September 2020 – ‘**Referral criteria to palliative care for patients with heart failure: A systematic review.**’ Patients with heart failure (HF) have significant symptom burden, care needs, and often a progressive course to end-stage disease. Palliative care (PC) referrals may be helpful, but it is currently unclear when patients should be referred and by whom. The authors identified 18 categories of referral criteria, including 7 need-based criteria and 10 disease-based criteria. This systematic review highlighted the lack of consensus regarding referral criteria for the involvement of PC in patients with HF. Further research is needed to identify appropriate and timely triggers for PC referral. **Abstract:** <https://bit.ly/3m7OxNY>

N.B. Additional articles on meeting the PC needs of patients living with HF noted in Media Watch 7 September 2020 (#682, pp.1-2). Search back issues of the weekly report for additional articles on this issue/topic at: <http://bit.ly/2ThijkC>

Perceptions of optimal end-of-life care in hospitals: A cross-sectional study of nurses in three locations

JOURNAL OF ADVANCED NURSING | Online – 4 September 2020 – Nurses’ perceptions of optimal end-of-life care (EoLC) are associated with location, but perhaps not in the direction that stereotypes would suggest. Findings of this study highlight the importance of developing and implementing location-specific approaches to optimize EoLC in hospitals. 582 nurses from Australia, Hong Kong and South Korea participated. The top five indicators rated by participants included: “physical symptoms managed well”; “private rooms and unlimited visiting hours”; “spend as much time with the patient as families wish”; “EoLC documents stored well and easily accessed”; and, “families know and follow patient’s wishes.” These findings may be useful to guide education and policy initiatives in Asian and Western countries that stress that EoLC is more than symptom management. Indicators can be used to collect data that help quantify differences between optimal care and the care actually being delivered, thereby determining where improvements might be made. **Abstract:** <https://bit.ly/35c9h11>

Related:

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 9 September 2020 – “‘**Challenging professional boundaries**’”: **A grounded theory study of health professionals’ first experiences of end-of-life care in hospital.**’ The theoretical model the authors conceptualized evidenced three phases: 1) Building a relationship between patient/family and professionals; 2) The disrupting impact; and, 3) The reaction phase. Analysis highlights the initial strong impact of this experience, which brought professionals to perceive emotional suffering and feelings of inadequacy. The new aspect the authors theory revealed is that all the categories are pertinent to all the professionals involved, therefore they explain important aspects of interprofessional collaboration in end-of-life care. **Abstract (w. list of references):** <https://bit.ly/3hj29IU>

Cont.

Noted in Media Watch 31 August 2020 (#681, p.11):

- *PALLIATIVE MEDICINE* | Online – 28 August 2020 – ‘Hospital patients’ perspectives on what is essential to enable optimal palliative care: A qualitative study.’ Results of this study confirmed and added depth of understanding to domains previously identified as important for optimal hospital palliative care, including: effective communication and shared decision making; expert care; adequate environment for care; family involvement in care provision; financial affairs; maintenance of sense of self/identity; minimising burden; respectful and compassionate care; trust and confidence in clinicians; and, maintenance of patient safety. Two additional domains were noted to be important: nutritional needs; and, access to medical and nursing specialists. **Abstract (w. list of references):** <https://bit.ly/2D8EGpC>

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

- *PALLIATIVE MEDICINE* | Online – 5 February 2020 – ‘Healthcare providers’ views and experiences of non-specialist palliative care in hospitals: A qualitative systematic review and thematic synthesis.’ Findings represent the views/experiences of 985 healthcare providers. 4 themes emerged; 1) Understanding of palliative care (PC); 2) Complexities of communication; 3) Hospital ecosystem; and, 4) Doctors and nurses – a different lens. Non-specialist PC in hospitals is operationalised as care in the last weeks/days of life. The organisation of acute care, inter-disciplinary working practices, clinician attitudes, poor communication structures, lack of education/training in PC principles exacerbates poor implementation of this care earlier for patients in hospitals. **Abstract (w. list of references):** <http://bit.ly/2RZx1OW>

Noted in Media Watch 4 November 2019 (#638, p.8):

- *BMC PALLIATIVE CARE* | Online 31 – October 2019 – ‘Dying in acute hospitals: Voices of bereaved relatives.’ This research provides a powerful snapshot in time into what works well and what could be improved in end-of-life care (EoLC) in acute hospitals. Findings are reported under several themes, including the overall quality of care, meeting care needs, communication, the hospital environment, and support for relatives. Improvements can be made that build on existing good practice that will enhance the experience of care for dying persons and their relatives. The study adds insights in relation to relative’s priorities for EoLC in acute hospitals and can advance care providers’, policy makers’ and educationalists’ priorities for service improvement. **Full text:** <http://bit.ly/324C42G>

Potentially inappropriate treatments at the end of life in nursing home residents: Findings from the PACE cross-sectional study in 6 European countries

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 September 2020 – Certain treatments are potentially inappropriate when administered to nursing home residents at the end of life (EoL) and should be carefully considered. An international comparison of potentially inappropriate treatments allows insight into common issues and country-specific challenges of EoL care in nursing homes and helps direct health-care policy in this area. A cross-sectional study of deceased residents in nursing homes (2015) in six European countries: Belgium (Flanders), England, Finland, Italy, The Netherlands and Poland. Potentially inappropriate treatments included: enteral administration of nutrition, parental administration of nutrition, artificial fluids, resuscitation, artificial ventilation, blood transfusion, chemotherapy/radiotherapy, dialysis, surgery, antibiotics, statins, antidiabetics, new oral anticoagulants. Nurses were questioned about whether these treatments were administered in the last week of life. This study involved 1,384 deceased residents from 322 nursing homes. In most countries, potentially inappropriate treatments were rarely used, with a maximum of 18.3% of residents receiving at least one treatment in Poland. Exceptions were antibiotics in all countries (between 11.3% in Belgium and 45% in Poland), artificial nutrition and hydration in Poland (54.3%) and Italy (41%) and antidiabetics in Poland (19.7%). Although the prevalence of potentially inappropriate treatments in the last week of life was generally low, antibiotics were frequently prescribed in all countries. In Poland and Italy, the prevalence of artificial administration of food/fluids in the last week of life was high, possibly reflecting country differences in legislation, care organization and culture, and the palliative care competences of staff. **Abstract (w. list of references):** <https://bit.ly/35fUMtf>



An exploratory study on sexuality in advanced disease and at the end of life from the perspective of palliative care professionals

MEDICINA PALIATIVA, 2020;27(2):88-97. The expression of sexuality is an important factor in the quality of life of patients with advanced disease or at the end of life. However, necessities in the area of sexuality are scarcely covered due to lack of consideration, capabilities, and trust of healthcare professionals. This exploratory study analyzes the perception of palliative care (PC) professionals on how sexuality is addressed, and how this should be handled in PC. Sexuality is recognized as an essential aspect of all human beings, and the responsibility to address needs in this area from a PC standpoint is assumed. However, its care is generally relegated to the sidelines. When addressed, it focuses largely on the affective and relational dimensions of people. Perceived lack of training on the matter, absence of specific guidelines in care plans, and time limits to building trust relations with patients are reported as reasons for the scarce attention sexuality draws in healthcare. Personal experiences and shame affect the level of care provided in relation to sexuality, as do social norms and taboos that hinder the expression of issues related with sexuality in healthcare. This study reveals failure to satisfy patient needs in this regard from a comprehensive perspective. **Abstract:** <https://bit.ly/3h6ruQ0>

Sociedad Española de Cuidados Paliativos

N.B. Spanish language article.

Noted in Media Watch 27 April 2020 (#663, p.9):

- *JOURNAL OF CLINICAL NURSING* | Online – 22 April 2020 – “**To live until you die could actually include being intimate and having sex**”: **A focus group study on nurses’ experiences of their work with sexuality in palliative care.** Nurses acknowledge the importance of addressing sexuality in palliative care (PC), as they express that they want to do right. Nurses appear to follow differing cultural, interpersonal and intrapsychic scripts on sexuality rather than knowledge-based guidelines. This underlines the importance of managers who safeguard the adherence to existing PC guidelines where sexuality is already included. It is important to be aware of norms to avoid excluding patients and partners that differ from the nurses themselves as well as from societal norms on sexuality. **Abstract:** <https://bit.ly/2XWFDJA>

Noted in Media Watch 28 October 2019 (#637, p.5):

- *ACTA MÉDICA PORTUGUESA*, 2019;32(10):625-627. **‘How prepared are we to address sexuality in palliative care?’** Sexuality, as one of the determinants of quality of life (QoL), includes different subjective dimensions related to identity, communication and intimacy. Sexuality “is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.” In this sense, intimacy as an important element of the expression of sexuality. This includes individual satisfaction with his/her affective, loving, and sexual relationships. For many patients, sexual health is an essential component of their QoL, providing a sense of normality and closeness within the couple. **Full text:** <http://bit.ly/2BvpQ8s>

N.B. Click on ‘Select Language’ to access full text in either English or Portuguese.

Nursing education on palliative care across Europe: Results and recommendations from the European Association for Palliative Care (EAPC) Taskforce on preparation for practice in palliative care nursing across the European Union based on an online-survey and country reports

PALLIATIVE MEDICINE | Online – 11 September 2020 – Nurses are the largest regulated group of healthcare professionals involved in palliative care (PC). In 2004, a taskforce of the EAPC launched the ‘Guide for Development of Palliative Nurse Education in Europe.’ No systematic evaluation of its impact in the development of PC education was undertaken. In 14 (56%) countries, PC was not identified as a mandatory subject within undergraduate nursing education. The EAPC guide is widely known and was/is being used in many countries to promote PC nursing education. Large variations were found across and within country responses. Wide awareness and use of the EAPC guide show how policy measures can influence the development of PC education. Recommendations are built and focus on both fostering the use of this guide and implementing policy measures to ensure that PC nursing is recognised and certified as a speciality in all European countries. **Abstract (w. list of references):** <https://bit.ly/2RfYQ4r>

Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation

PALLIATIVE MEDICINE | Online – 11 September 2020 – Public involvement is increasingly considered a prerequisite for high quality research. However, involvement in palliative care (PC) is impeded by limited evidence on the best approaches for populations affected by life-limiting illness. Building and maintaining relationships, taking a flexible approach and finding the “right” people are important for successful public involvement. Relationship building created a safe environment for discussing sensitive topics, although public members feel greater consideration of emotional support was needed. Flexibility supported involvement alongside unpredictable circumstances of chronic and life-limiting illness, and was facilitated by responsive communication, and opportunities for in-person and virtual involvement at a project- and institution-level. More opportunities for two-way feedback throughout projects is suggested. Within PC research, it is important for involvement to focus on building and maintaining relationships, working flexibly, and identifying those with relevant experience. Taking a strategic approach and developing adequate infrastructure and networks can facilitate public involvement within this field. **Abstract (w. list of references):** <https://bit.ly/33nroPn>

Managing and sharing research data in children’s palliative care: Risks, benefits and imponderables

JOURNAL OF ADVANCED NURSING | Online – 10 September 2020 – When the speciality of children’s palliative care was in its infancy, learning was based on experience and sharing good practice, but there is now an increasing emphasis on evidence-based interventions and care delivery, requiring the development of a robust and rigorous approach to research which will stand up to the highest levels of scrutiny. There is an expectation that during academic studies, publication of peer-reviewed papers or production of reports to funding bodies, this scrutiny will include access to the data collected as part of the research process. Access to research data by those outside the research team raises some important issues for research in this area, amplified by the challenges of research with a small population. In this editorial, the authors explore what this means for those conducting research and for participants in research. They highlight areas for further consideration to inform a conscientious approach in the future. **Full text:** <https://bit.ly/3hmiExQ>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *PATIENT EDUCATION & COUNSELING* | Online – 29 August 2020 – ‘**Clinical discussion of medical aid-in-dying: Minimizing harms and ensuring informed choice.**’ The implementation of medical aid-in-dying (MAiD) poses new challenges for clinical communication and counseling. Among these, healthcare providers must consider whether to initiate a discussion of MAiD with eligible patients who do not directly ask about it. Norms and policies concerning this issue vary tremendously across jurisdictions where MAiD is legally authorized, reflecting divergent assumptions about patients’ rights to information about end-of-life options and the purpose and potential harms of clinical disclosure. The authors draw on informed consent doctrine to analyze two policies concerning clinical communication about MAiD: the legal prohibition against provider-initiated discussions of MAiD in Victoria, Australia, and the Canadian Association of MAiD Assessors & Providers position that providers have an ethical and professional responsibility to inform eligible patients about MAiD. Informed consent requires that clinicians strike a balance between minimizing potential harms to patients caused by initiating discussions of MAiD and the imperative to inform and counsel patients about all of their legally available medical options. Clinicians should be aware of both the importance of communication as a tool to inform patients and the potential for clinical language to cause harm to or to unduly influence patients. **Abstract:** <https://bit.ly/2FoCfjm>

N.B. In Canada, MAiD stands for “medical assistance in dying.”



Palliative Care Network
Palliative Care for Everyone, Everywhere

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

Publishing Matters

Money down the drain: Predatory publishing in the COVID-19 era

CANADIAN JOURNAL OF PUBLIC HEALTH | Online – 4 September 2020 – For years, predatory journals have exploited authors by soliciting papers through email and social media, offering to publish articles open access quickly and with minimal review, often with a fee. The publish-or-perish mentality in academia and barriers for researchers from low- and middle-income countries (LMICs) to publish led to a surge of predatory journals offering an easy way out. This conceals research from the scientific community, impeding scientific advancement and affecting authors' reputation. Upon receiving multiple requests from predatory journals to publish manuscripts related to the coronavirus disease 2019 (COVID-19), the authors assessed the scope of exploitative practices these journals engaged in by soliciting and publishing COVID-19 articles and earning off of vulnerable authors in a time where novel and accurate information is highly needed. Their findings are in line with previous evidence of unethical practices by predatory journals, including scripted mail invitations, smaller but additive publication fees – which disproportionately affect LMIC researchers – and sham reviews. In the context of the pandemic, there are three major concerns: 1) Loss of potentially valuable biomedical and epidemiological information; 2) Spread of misinformation with potentially harmful or negligent consequences (e.g., some articles claimed efficacy of homeopathy); and, 3) Money earned off of unknowing authors in times where many scientists and clinicians have taken pay cuts. **Full text:** <https://bit.ly/33eIQFI>

A qualitative content analysis of watchlists vs safelists: How do they address the issue of predatory publishing?

JOURNAL OF ACADEMIC LIBRARIANSHIP, 2020;46(6):102236. Predatory journals and publishers are a growing concern in the scholarly publishing arena. As one type of attempt to address this increasingly important issue, numerous individuals, associations, and companies have begun curating journal watchlists or journal safelists. This study uses a qualitative content analysis to explore the inclusion/exclusion criteria stated by scholarly publishing journal watchlists and safelists to better understand the content of these lists, as well as the larger controversies that continue to surround the phenomenon that has come to be known as predatory publishing. Four watchlists and ten safelists were analyzed through an examination of their published mission statements and inclusion/exclusion criteria. Notable differences that emerged include the remaining influence of librarian Jeffrey Beall in the watchlists, and the explicit disavowal of his methods for the safelists, along with a growing recognition that the “list” approach may not fully address systemic aspects of predatory publishing that go beyond the individual author's ethical decision-making agency. **Full text:** <https://bit.ly/3m9pNoF>



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>



Media Watch: Behind the Scenes
<http://bit.ly/2MwRRAU>

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.

Distribution

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2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

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/2DKhnCO>

[Scroll down to 'Media Watch: The ICU and ACP']

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
Hospice Palliative
Care Network

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']

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09.08.2020

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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/2RgTvYr>

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>

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