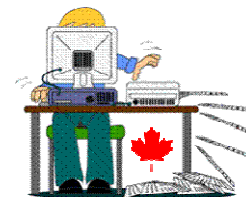


Media Watch...

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

Clinical experience and research suggest that families remember the compassion of the clinician over the words used when bad news is delivered with empathy, intention, and honesty.

'Pediatric palliative care in a pandemic: Role obligations, moral distress, and the care you can give' (p.17), in *Pediatrics*.

Canada

Coronavirus public health restrictions shouldn't mean dying alone

BRITISH COLUMBIA | *The Conversation* – 28 May 2020 – One of the most heartbreaking aspects of the COVID-19 physical distancing has been accounts of people dying alone in hospital or in long-term care (LTC) facilities. These incidents have not only devastated family members but also disturbed many people with the sense that something has gone wrong with how our society cares for aging or vulnerable people and responds to illness and and dying. The British Columbia Centre for Disease Control guidelines suggest that there is indeed room for “essential visits” in LTC facilities. These are described as including but not being limited to “visits for compassionate care (end of life and critical illness), visits considered paramount to resident care and well-being, such as assistance with feeding or mobility....” But there is a great deal of room for interpretation of what constitutes an essential visit. One might argue that those in LTC are not imminently dying and so perhaps the right of family to be present does not outweigh the risks of COVID-19. Firstly, however, families with people in LTC will tell you that their visits are essential. The COVID-19 crisis has revealed many of the fault lines in our LTC system. Those

in residential or LTC can be at risk and it is often the vigilance of family members that ensure that these vulnerable persons receive adequate care. A family member who visits regularly is a powerful surveillance system. Secondly, what health-care practitioners call an “end-of-life situation” exists, in fact, on a continuum. The Office of the Seniors Advocate British Columbia notes that the average length of stay for residents in LTC is 871 days – less than two-and-a-half years. That means that if following best practices, all people residing in LTC should receive a palliative approach to care. <https://bit.ly/3dlthQo>

Specialist Publications

'Does the public feel prepared to be substitute decision-makers? Gaps in preparedness and support for a high school curriculum: A national survey' (p.6), in *Age & Ageing*.

'Perspectives of Nunavut patients and families on their cancer and end-of-life care experiences' (p.12), in *International Journal of Circumpolar Health*.

Cont.

Noted in Media Watch 18 May 2020 (#666, p.14):

- **PALLIATIVE & SUPPORTIVE CARE** | Online – 15 May 2020 – ‘**The relationship between caregivers’ perceptions of end-of-life care in long-term care and a good resident death.**’ 78 participants whose relative or friend died in one of five long-term care (LTC) homes in Canada completed questionnaires on their perceptions of end-of-life care and perceptions of a good resident death. Findings confirm the critical role staff in LTC play in supporting caregivers’ perceptions of a good resident death. By keeping caregivers informed about expectations at the end of life, staff can enhance caregivers’ perceptions of a good death. By addressing spiritual issues staff may improve caregivers’ perceptions residents were at peace when they died. **Abstract (w. list of references):** <https://bit.ly/3cDyBOz>

N.B. Additional articles on end-of-life care in LTC homes noted in 27 April 2020 issue of Media Watch (#663, p.8).

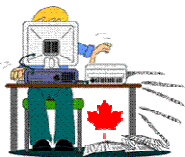
Paramedics launch palliative care pilot project

ONTARIO | *The Woodstock Sentinel-Review* – 28 May 2020 – Palliative care (PC) patients in Oxford County will now be able to receive some treatment at home, thanks to a new pilot project that deploys paramedics to help with end-of-life care (EoLC). The project – created in response to the COVID-19 pandemic – will run until 31 October 2020, helping make sure PC patients continue to receive EoLC even as the pandemic absorbs much of the healthcare system’s capacity. Doctors of PC patients will work with paramedics to help manage symptoms and prevent visits to the emergency department, Oxford County said in a statement announcing the program. The pilot program will run alongside Oxford’s PC outreach team, which provides care for registered palliative patients, and the Southwest Local Health Integration Network. Paramedics in the program have undergone special PC and personal protective equipment training. Throughout the pandemic, Oxford County paramedics have stepped up in other areas too. Paramedics became part of a program to conduct community-based COVID-19 testing for people unable to leave their homes or visit a testing centre, and have been instrumental in receiving and organizing shipments of personal protective equipment coming into the county. <https://bit.ly/3er0o56>

Noted in Media Watch 17 February 2020 (#653, p.2):

- ONTARIO | *The Ottawa Citizen* – 10 February 2020 – ‘**Ottawa paramedics to get new powers to treat palliative patients at home.**’ Currently, under provincial law, paramedics are required to take palliative care patients in need of pain or symptom relief who call 911 to an emergency department for treatment. A pilot project allows eligible patients to have the option of being treated at home after calling 911. The province’s Ambulance Act and Health Insurance Act will be amended to allow for the change. Ottawa paramedics will receive special training to assess the patient’s condition when they arrive. They will be able to administer medication for pain relief, shortness of breath, hallucinations, agitation, nausea, vomiting and congested breathing. <http://bit.ly/2Sw6l25>

N.B. Additional articles on the role of paramedics in PC noted in 20 January 2020 issue of Media Watch (#649, p.9).



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>

U.S.A.

More people are dying in American prisons – here’s how they face the end of their lives

THE CONVERSATION | Online – 27 May 2020 – Outbreaks of coronavirus have hit prison populations particularly hard – but for many inmates in the U.S., illness and the prospect of dying behind bars already existed. Advocacy groups have flagged concerns about disease transmission, lack of medical care and deaths in custody as a result of COVID-19. But deaths in custody are not a new phenomena and the process of dying with dignity while incarcerated is complicated. Prisoners grow old faster and become sick earlier. By 2030 some experts believe that one in three prisoners will be over the age of 55, increasing the likely population of prisoners diagnosed with conditions such as cancer, heart disease, liver and kidney disease, high blood pressure and diabetes. A recent Bureau of Justice Statistics report revealed a startling increase in state prisoner mortality. Between 2006 and

2016, the last year for which the study provided data, there were more than 53,000 deaths in custody. More than half of the 3,739 deaths in custody in 2016 resulted from just two illnesses – cancer (30%) and heart disease (28%). The proportion of prisoners requiring end-of-life care is twice as high as the general population.¹ <https://bit.ly/2X8xpO0>

Specialist Publications

“‘We are here to assist all individuals who need hospice services’”: Hospices’ perspectives on improving access and inclusion for racial/ethnic minorities’ (p.11), in *Gerontology & Geriatric Medicine*.

1. ‘Prevalence and characteristics of prisoners requiring end-of-life care: A prospective national survey,’ *Palliative Medicine*, published online 8 August 2017. [Noted in 21 August 2017 issue of Media Watch (#526, p.17)] Full text: <https://goo.gl/5pa3Jh>

N.B. 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>

Pandemic hits hospice revenues

HOSPICE NEWS | Online – 26 May 2020 – As the novel coronavirus pandemic continues disrupting the business of hospice, many providers anticipate a decrease in annual revenues for 2020...¹ Among the contributing factors to revenue drops is a decline in hospice patient admissions and referrals amid the public health emergency. 60% of the hospices surveyed anticipated a decrease in annual revenues due to the pandemic’s pitfalls, “with just under 30% expecting a decrease of 15% or more” during calendar year 2020. Majority of the providers cited increased costs of supplying staff with personal protective equipment (PPE) as a driving force... Closely following PPE costs, reductions in patient referrals and admissions also topped the list of contributing factors. More than half of the hospices surveyed saw a decrease in patient admissions in comparison to last March, with more than a quarter seeing a 15% drop or more.

Despite a rise in confirmed COVID-19 positive patients coming on to service, nearly 71% of these hospices reported declining referrals and admissions from nursing facilities, along with 63% experiencing declines in hospital referrals and roughly half seeing a decrease from community referral partners. <https://bit.ly/3c8vwVs>

COVID-19: End-of-Life Care

‘National outreach of telepalliative medicine volunteers for a New York City safety net system COVID-19 pandemic response’ (p.17), in *Journal of Pain & Symptom Management*.

‘Development of a palliative care toolkit for the COVID-19 pandemic’ (p.17), in *Journal of Pain & Symptom Management*.

1. ‘Hospice in the Time of COVID-19...,’ National Association for Home Care & Hospice,’ May 2020. Download/view at: <https://bit.ly/2X4cTOu>

Hospices mobilize dedicated COVID teams

HOSPICE NEWS | Online – 22 May 2020 – Hospices nationwide are designating specific interdisciplinary clinicians who work exclusively with COVID-positive patients to reduce risk to the rest of their staff and vulnerable patient populations. Selecting staff to serve on dedicated COVID teams has involved several considerations and additional measures as hospices work to minimize exposure. In many cases, COVID-dedicated teams have consisted of primarily staff who volunteered to serve patients testing positive including nurses, nursing aides, physicians and even clinical leadership. Developing criteria for COVID team members was an early challenge for hospice providers as these teams began to take shape. Staff across hospice organizations nationwide have received additional training in compliance with federal, state and local safety protocols intended to minimize the pandemic's spread. Dedicated COVID teams are especially trained in understanding the disease's spread and impact, along with effective screening and infection prevention methods, as they put their own health and families at risk serving infected patients. Dedicated COVID teams need to have the ability to address more than just the medical needs of patients. With accessibility to patients limited amid social distancing measures to slow the pandemic's spread, training in providing telehealth utilization has been increasingly important to continue providing spiritual and grief support, social services and counseling. <https://bit.ly/3cXDPF6>

Grief in the time of COVID-19

SCIENTIFIC AMERICAN | Online – 22 May 2020 – With the COVID-19 death toll in the U.S. at over 80,000 as of mid-May, we are witnessing an extraordinary onslaught of severe illness and death. The world has only just begun to experience the collective grief that we are all facing – and because we're self-isolating and avoiding crowds, we won't be able to practice the rituals that help us process this difficult emotion. We won't have access to typical kinds of grief support. We don't even have the language to describe it. Grief left untended has long-term consequences to mental, emotional and physical health that could impact individuals and communities far into the future. Complicated grief presents with extended time periods of heightened experiences of bereavement that disrupt normal functioning and sometimes include suicidality. The pain of loss is real, and we have yet to scratch the surface of understanding how this will look in a post-COVID-19 world. With family and friends unable to say their final goodbyes, nurses and doctors are left to fill the void by holding the hands of a stranger and joining virtual family meetings in which they discuss end-of-life care or relay the news of a death. The toll on these clinicians, who may not be trained in grief counseling – and who are also carrying their own burdens of stress and sadness – could be enormous. Meanwhile, those who are trained, including palliative care and hospice teams (which tend to be in limited supply at the best of times), are overstretched beyond their capacity to be of comfort. <https://bit.ly/2WYkimg>

Related:

- *HOSPICE NEWS* | Online – 26 May 2020 – **'Hospices help families address disenfranchised grief.'** Hospices routinely provide bereavement care ... but increasingly during the COVID-19 pandemic they are seeing more people afflicted with disenfranchised grief. Disenfranchised grief is a form of bereavement that is not acknowledged as legitimate by others or even by the families themselves. Research indicates that disenfranchised grief can extend and intensify the grieving experience, interfere with a person's processing of grief and lead to decreased social support during bereavement, as well as exacerbate sadness, anger, guilt and loneliness. Some bereaved individuals self-disenfranchise, in which they question the validity of their own experience. <https://bit.ly/2ZD323P>



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International

Calls for palliative care reform in post COVID-19 world

AUSTRALIA | Palliative Care Australia (PCA) – 26 May 2020 – A new report ... has called for an overhaul of the palliative care (PC) system in Australia, calling for an additional annual investment of \$365 million to bring the system up to speed in a post COVID-19 world.¹ The report is also calling for a national agreement on PC between the Commonwealth and the states and territories, and a new full-time Palliative Care Commissioner, to help create the best experience possible for those with life-limiting conditions and those around them. “All Australians who need PC are simply not having access to services when they need to, particularly at home and in community settings. As we prepare for an ageing population and other unexpected stresses to our healthcare system, like COVID-19, we must look seriously at reforming our system to ensure it can meet people’s needs into the future,” PCA Chair Professor Meera Agar said. “PC is about quality of life, living well with a palliative diagnosis and about dying well. Through an additional annual investment of \$365 million on national reform, we can save up to \$464 million in other health system costs while making the system work best for those experiencing it. We have to spend money to save money and that’s backed by leading economists.” The report ... found that if people can be supported with PC outside of institutional settings, they can live well and die in a place of their choosing, for example, at home. In practice however, very few Australians are achieving this. The report ... highlights practical “win-win” opportunities to help address current shortfalls. <https://bit.ly/3eyXBqE>

1. ‘Investing to Save – The economics of increased investment in palliative care in Australia,’ Palliative Care Australia, May 2020. **Download/view at:** <https://bit.ly/3d8DFL2>

Related:

- **AUSTRALIAN AGEING AGENDA** | Online – 27 May 2020 – ‘**COVID-19 places spotlight on dying alone.**’ There have been countless reports ... of people dying alone, both because older people are separated from their families, and because resource-constrained healthcare systems struggle to maintain presence at the bedside of a person approaching the end of life (EoL). Dying alone ... challenges our cultural norms and ideals about the EoL, namely being surrounded by loved ones. Being denied access to a dying loved one ... also has profound psychological and practical consequences for families. And distancing measures during the pandemic have unsettled our cultural practices after death, as family members have been unable to physically congregate to grieve. <https://bit.ly/2ZG9yqr>

COVID-19: End-of-Life Care

‘**Can video consultations replace face-to-face interviews? Palliative medicine and the COVID-19 pandemic: Rapid review**’ (p.16), in *BMJ Supportive & Palliative Care*.

‘**Compassionate communication and end-of-life care for critically ill patients with SARS-Cov-2 infection**’ (p.16), in *Journal of Clinical Ethics*.

Specialist Publications

‘**Community health workers in palliative care provision in low-income and middle-income countries: A systematic scoping review of the literature**’ (p.9), in *BMJ Global Health*.

‘**European Academy of Neurology guideline on palliative care of people with severe, progressive multiple sclerosis**’ (p.10), in *European Journal of Neurology*.

‘**Does the International Narcotics Control Board sufficiently prioritise enablement of access to therapeutic opioids? A systematic critical analysis of six INCB annual reports, 1968-2018**’ (p.14), in *Journal of Global Health Reports*.

‘**Global development of children’s palliative care: The picture in 2017**’ (p.19), in *Wellcome Open Research*.

Specialist Publications

Does the public feel prepared to be substitute decision-makers? Gaps in preparedness and support for a high school curriculum: A national survey

AGE & AGEING | Online – 27 May 2020 – Substitute decision-makers (SDMs) make decisions on behalf of patients who do not have capacity, in line with previously expressed wishes, values and beliefs. However, miscommunications and poor awareness of previous wishes often lead to inappropriate care. Increasing public preparedness to communicate on behalf of loved ones may improve care in patients requiring an SDM. The authors conducted an online survey with a representative sample of the Canadian population. The primary outcome was self-reported preparedness to be an SDM. The secondary outcome was support for a high school curriculum on the role of SDMs. Of 1,000 participants, 53.1% felt prepared to be an SDM, and 75.4% stated they understood their loved one's values. However, only 55.6% reported having had a meaningful conversation with their loved one

about values and wishes, and only 61.7% reported understanding the SDM role. Engagement in advance care planning for oneself was low (23.1%). Age, experience, training and comfort with communication were associated with preparedness in our multivariate analysis. A high school curriculum was supported by 61.1% of respondents, with 28.3% neutral and 10.6% against it. **Abstract:** <https://bit.ly/3en3x66>

Publishing Matters

'A methodological review of mixed methods research in palliative and end-of-life care (2014-2019)' (p.20), in *International Journal of Environmental Research & Public Health*.

N.B. See 'Gaps in public preparedness to be a substitute decision-maker and the acceptability of high school education on resuscitation and end-of-life care: A mixed-methods study,' *CMAJ Open*, published only 16 September 2019. [Noted in 23 September 2019 issue of *Media Watch* (#632, p.9). **Full text:** <http://bit.ly/2IVwUqk>

Clinicians' and public acceptability of universal risk-of-death screening for older people in routine clinical practice in Australia: Cross-sectional surveys

AGING CLINICAL & EXPERIMENTAL RESEARCH | Online – 26 May 2020 – Clinicians' delays to identify risk of death and communicate it to patients nearing the end of life contribute to health-related harm in health services worldwide. This study sought to ascertain doctors, nurses and senior members of the public's perceptions of the routine use of a screening tool to predict risk of death for older people. The authors undertook a cross-sectional online, face-to-face and postal survey of 360 clinicians and 497 members of the public. Most (65.9%) of the members of the public welcomed (and 12.3% were indifferent to) the use of a screening tool as a decision guide to minimise overtreatment and errors from clinician assumptions. The majority of clinicians (75.6%) reported they were likely or very likely to use the tool, or might consider using it if convinced of its accuracy. A minority (13.3%) stated they preferred to rely on their clinical judgement and would be unlikely to use it. The concept of integrating prognostication of death in routine practice was not resisted by either target group. Screening for risk of death is seen as potentially useful and suggests the readiness for a culture change. Future research on implementation strategies could be a step in the right direction. **Abstract (w. list of references):** <https://bit.ly/2XC4e4G>

A systematic review of clinical interventions facilitating end-of-life communication between patients and family caregivers

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 28 May 2020 – This systematic review aimed to examine the evidence for the efficacy of healthcare professional-led interventions in enhancing communication between patients and family caregivers. Of 2,955 articles retrieved, 8 meeting the authors' eligibility criteria were included in the review. All 8 studies employed psycho-educational interventions involving both patients and surrogate/family caregivers. Common elements of the interventions reviewed included encouraging participant dyads to share their concerns about the patient's medical condition, clarify their goals and values for end-of-life care (EoLC), and discuss their EoLC preferences. Of 8 interventions reviewed, 6 measured EoLC preference congruence within dyads as a primary outcome, and all 6 interventions were effective in increasing congruence. Secondary outcomes measured included decisional conflict and relationship quality, with mixed outcomes reported. This review suggests that healthcare professional-led EoLC communication interventions show promise for improving EoLC preference congruence. However, further studies with improved methodological rigor are needed to establish the optimal timing, intensity, and duration of interventions. **Abstract (w. list of references):** <https://bit.ly/2B38Rx0>

Exploring patient-reported barriers to advance care planning in family practice

BMC FAMILY PRACTICE | Online – 25 May 2020 – The findings of this multi-site, cross-sectional study indicate that lack of awareness about advance care planning (ACP) and not seeing ACP as a priority were key challenges among patients who reported a barrier to ACP discussions. Further, even when aware of the importance of ACP, patients may not feel that it is their role to initiate the discussion with their physician or family members. It may be possible to address this reluctance through the unique longitudinal relationship that family physicians have with their patients and through a focused effort to bring the ACP conversation into the forefront of routine preventive care. With better patient education, a preventive focus situated in the ongoing longitudinal family physician-patient relationship, and appropriate funding models, ACP discussions could happen at appropriate times (e.g., after hospitalizations, when health status undergoes a significant change, at routine visits for older adults) and could help patients receive the care that respects their goals and values in their future care or if they are not able to speak for themselves. **Full text:** <https://bit.ly/2B3Kory>

Noted in Media Watch 27 January 2020 (#650, p.6):

- *CANADIAN FAMILY PHYSICIAN*, 2020;66(1):e21-e29. **'Family physicians' perspectives on advance care planning in community-dwelling elderly patients.'** The authors found family physicians felt responsible for playing a leading role in advance care planning (ACP)... They also had different thresholds for initiating these conversations, with some physicians addressing ACP before and others during a health crisis. This variation can be attributed to differing ideas about the role and effects of palliative care, previous patient encounters, and physician-specific factors. For the latter, physicians who solely practised in the clinic setting revealed that they frequently were not aware of the effects of ACP, owing to decreased interaction with patients near the end of life. **Full text:** <http://bit.ly/3aGSaET>

Noted in Media Watch 23 March 2020 (#658, p.6):

- *CRITICAL CARE EXPLORATIONS* | Online – Accessed 15 March 2020 – **'Estimating the impact of words used by physicians in advance care planning discussions: The "Do you want everything done?" effect.'** Healthcare providers who engage in advance care planning discussions with patients and their substitute decision-makers (SDMs) should never use the phrase "Do you want everything done?" as part of soliciting a patient's goals-of-care and advance directives. By using this phrase, not only are they asking for informed consent to provide an intervention that does not exist, but they are also potentially exposing both the patient and their SDM to a future of needless suffering. **Full text:** <http://bit.ly/2U8Vrp3>

Relationship of place of death with care capacity and accessibility: A multilevel population study of system effects on place of death in Norway

BMC HEALTH SERVICES RESEARCH | Online – 24 May 2020 – There is substantial variation in the place of death (PoD) between municipalities and hospital districts in Norway, not only reflecting differences in decedents' characteristics, but also local circumstances, such as nearness to hospital and service capacities. It has been a core value for palliative care to enable people to make choices about their end-of-life care (EoL) and PoD. People generally prefer to die at home, and Norway has a low proportion of home deaths compared with other countries. The proportion of home deaths varies considerably between local communities. Increasing the availability of home care services will likely provide people a more active voice in the decisions tied to their PoD, allowing more people to die at home, if that is what they prefer. These findings may have important policy implications for the EoLC in other countries with demographic and epidemiological trajectories similar to those in Norway. Further studies in other national contexts should be undertaken to support such conclusions. **Full text:** <https://bit.ly/3gobCJq>

Noted in Media Watch 3 February 2020 (#651, p.7):

- *FAMILY PRACTICE* | Online – 29 January 2020 – '**General practitioners' provision of end-of-life care and associations with dying at home: A registry-based longitudinal study.**' This population-based analyses showed that GP home visits and interdisciplinary collaboration increased the odds that people died at home. People leaving their home for GP consultations or out-of-hours contacts or those who were hospitalized were less likely to die at home. Overall, 9.2% received home visits during the last 4 weeks of life, of which a third died at home. Only 6.6% additionally had GPs involved in interdisciplinary collaboration. Over a third of people were hospitalized during the last week of life. These findings are important for clinicians and policy-makers. **Full text:** <http://bit.ly/2Sdqu90>

End-of-life care in a pediatric intensive care unit: The impact of the development of a palliative care unit

BMC PALLIATIVE CARE | Online – 28 May 2020 – Fewer children died in the authors' pediatric intensive care unit (PICU) in recent years, and the life-support limitation (LSL) proportionally increased, although the percentage is still relatively low. In this 15-year retrospective study, a large percentage of the cases had a chronic disease. The main cause of LSL in the PICU was the unfavorable evolution of the underlying pathology. Families were involved in the end-of-life (EOL) decision-making process. Withdrawal was the most frequent LSL. Withdrawing mechanical ventilation and oxygen were the main actions taken. Undoubtedly, the focus on holistic, compassionate, and child-centered care within the PICU helps achieve a dignified EoL in which the parents are also involved in the decision-making process and the care provided to their children. Increased confidence among the clinicians working in the PICU when providing EoL care, as well as the availability of a palliative care unit, contribute to this improvement in quality EoL care. **Full text:** <https://bit.ly/2XcdDAT>

Pediatric palliative care in a pandemic: Role obligations, moral distress, and the care you can give

PEDIATRICS | Online – 26 May 2020 – Many ethical issues arise concerning care of critically ill and dying patients during the COVID-19 pandemic. The authors present two cases that highlight two different sorts of ethical issues. One is focused on the decisions that have to be made when the surge of patients with respiratory failure overwhelm ICUs. The other on the psychological issues that arise for parents who are caring for a dying child when infection-control policies limit the number of visitors. Both raise challenges for caregivers who are trying to be honest, to deal with their own moral distress, and to provide compassionate palliative care. **Full text (click on pdf icon)** <https://bit.ly/3d7X2E4>

Cont.

Noted in Media Watch 11 May 2020 (#665, p.4):

- *CURRENT OPINION IN PEDIATRICS*, 2020;32(3):428-435. ‘**Palliative care for pediatric intensive care patients and families.**’ This article reviews current evidence and best practices for integrating palliative care (PC) into the pediatric intensive care unit (PICU)... PC is best integrated in a tiered approach, with primary PC provided by the PICU and surgical providers for all patients and families, including basic symptom management, high-quality communication, and end-of-life care. Secondary and tertiary levels of care involve unit or team-based “champions” with additional expertise, and subspecialty PC teams, respectively. This review provides a framework and tools to enable PICU and surgical providers to integrate PC best practices into patient and family care. **Abstract:** <https://bit.ly/35DkOoB>

N.B. Additional articles on PC in PICUs noted in 9 March 2020 issue of Media Watch (#656, p.5).

Community health workers in palliative care provision in low-income and middle-income countries: A systematic scoping review of the literature

BMJ GLOBAL HEALTH, 2020;5(5):e002368. The 13 studies included in this review all took place in sub-Saharan African countries or in India. Despite the limited evidence base, the authors found that community health workers (CHWs) have several roles in palliative care (PC) provision in low-income and middle-income (LMIC) settings. These include raising awareness in the community, provision of pain management services, home-based care delivery and visitation, and provision of psychological support and spiritual guidance. Several areas of weakness were also identified, including a lack of details surrounding the training and ongoing support of CHWs, as well as the financial costs associated with deploying CHWs in the provision of PC services. There is a need for countries to develop their own specific guidelines for the roles CHWs should play in PC, so that any initiatives are appropriate for the context in which they are being implemented. Finally, it is important to emphasise that CHWs cannot function in isolation to address the burden of PC needs in LMICs. Key stakeholders from various domains, including local government and policymakers, must value, advocate for and work in conjunction with CHWs to ensure PC, which is a basic human right, can be accessed by all. **Full text:** <https://bit.ly/3d61K5i>

Barriers to hospice and palliative care research: A patient-centered approach to intervention studies

CLINICAL JOURNAL OF ONCOLOGY NURSING, 2020;24(3):227-230. Overcoming barriers in hospice and palliative care (PC) research is a multifaceted challenge for researchers conducting intervention studies. The complexity and variations of these barriers are abundant and serious in nature and can threaten the success of intervention research for the hospice and PC patient population. This article explores how challenges and barriers to intervention research can be mitigated by nurses caring for patients in hospice and PC settings. **Abstract:** <https://bit.ly/2Aa9Xa4>

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

- *BMC PALLIATIVE CARE* | Online – 3 February 2020 – ‘**International palliative care research priorities: A systematic review.**’ The authors call attention to the need for more end users in research priority setting exercises, therefore, researchers and funding bodies should develop new strategies to ensure meaningful participation of palliative care (PC) patients and families, building in structures and processes to account for the vulnerability often present within this population. Findings of this review provide an initial blueprint for PC research funders and policymakers to contribute to the future research agenda for PC from a patient and healthcare professional perspective. These findings may help to inform this debate. **Full text:** <http://bit.ly/37VsJxS>

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

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

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

Evaluating the outcomes of an organizational initiative to expand end-of-life resources in intensive care units with palliative support tools and floating hospice

DIMENSIONS OF CRITICAL CARE NURSING, 2020;39(4):219-235. There is evidence that palliative care (PC) and floating (inpatient) hospice can improve end-of-life (EoL) experiences for patients and their families in the intensive care unit (ICU). However, both PC and hospice remain underutilized in the ICU setting. This study examined palliative consultations and floating hospice referrals for ICU patients during a phased launch of floating hospice, two palliative order sets, and general education to support implementation of PC guidelines. After the initial introduction of floating hospice, 27% of the patients received referrals; however, referrals did not significantly increase over time. Of the 68 patients who received a floating hospice referral (24%), only 38 were discharged to floating hospice. This study provided the organization with vital information about their initiative to expand EoL resources. Utilization and timing of palliative consults and floating hospice referrals were lower and later than expected, highlighting the importance of developing purposeful strategies beyond education to address ICU cultural and structural barriers. **Abstract:** <https://bit.ly/2M6hJEg>

European Academy of Neurology guideline on palliative care of people with severe, progressive multiple sclerosis

EUROPEAN JOURNAL OF NEUROLOGY | Online – 29 May 2020 – Patients with severe, progressive multiple sclerosis (MS) have complex physical and psychosocial needs, typically over several years. Few treatment options are available to prevent or delay further clinical worsening in this population. The objective was to develop an evidence-based clinical practice guideline for the palliative care of patients with severe, progressive MS. Areas that currently lack evidence of efficacy include advance care planning, the management of symptoms such as fatigue and mood problems in this population, and interventions for caregivers and health professionals. **Full text:** <https://bit.ly/36IPC7T>

Noted in Media Watch 28 October 2019 (#637, p.7):

- *COCHRANE DATABASE OF SYSTEMATIC REVIEWS* | Online – 22 October 2019 – ‘**Palliative care interventions for people with multiple sclerosis.**’ The studies included in this review compared palliative care (PC) delivered in home visits versus usual care for people with multiple sclerosis. Interventions focused on assessment and management of symptoms and end-of-life planning. The authors are uncertain about differences between PC versus usual care for the following outcomes assessed at long-term follow-up: change in health-related quality of life, adverse events, and hospital admission. The included studies did not assess fatigue, cognitive function, relapse-free survival or sustained progression-free survival. **Abstract:** <http://bit.ly/2qvW94C>

Noted in Media Watch 5 August 2019 (#625, p.12):

- *MULTIPLE SCLEROSIS & RELATED DISORDERS* | Online – 20 July 2019 – ‘**Assessing palliative care for multiple sclerosis: A qualitative study of a neglected neurological disease.**’ Improving access to palliative care (PC) for multiple sclerosis (MS) requires a contextual understanding of how PC is perceived by patients and health professionals, the existing care pathways, and barriers to the provision of PC. Patients and neurologists [i.e., study participants] mostly associated PC with the end-of-life and struggled to understand the need for PC in MS. Another barrier was the lack of understanding about the PC needs of MS patients. PC physicians also identified the scarcity of resources and their lack of experience with MS as barriers. **Abstract:** <http://bit.ly/2Mnv2lj>

Findings from the first round of the National Audit of Care at the End of Life (NACEL)

FUTURE HEALTHCARE JOURNAL, 2020;7(Suppl):s36. NACEL is a national comparative audit of the quality and outcomes of care experienced by the dying person [in the U.K.] and those important to them during the last admission leading to death in acute, community hospitals and mental health inpatient providers in England and Wales. Documentation that a person may die imminently was high. For half of patients, imminent death was recognised less than one and a half days before they died, leaving a limited amount of time to discuss and implement an individual plan of care. People's experience of care was good, excellent or outstanding in most cases (80%), as reported by the quality survey. However, 20% felt that there was scope to improve the quality of care and sensitive communication with both the patient and the family/ others. Governance of end-of-life care was strong. Improvement is required in the documentation of an individual plan of care (there was documented evidence of a plan for 62% of people who died). Similarly, for one-third of people who died, a discussion about the plan of care, and discussions about medication, hydration and nutrition, had not been recorded. The full audit findings from the first round were published in July 2019.¹ The second round of NACEL is running in 2019/2020 and data collection is currently underway, involving acute and community hospital providers. **Full text (click on pdf icon):** <https://bit.ly/2AZHcNs>

1. 'National Audit of Care at the End of Life: 2018-2019 Report,' Healthcare Quality Improvement Partnership, July 2019. [Noted in 15 July 2019 issue of Media Watch (#622, p.6)] **Download/view at:** <http://bit.ly/2LhXa9J>

Hospice in the U.S.

“We are here to assist all individuals who need hospice services”: Hospices’ perspectives on improving access and inclusion for racial/ethnic minorities

GERONTOLOGY & GERIATRIC MEDICINE | Online – 19 May 2020 – Racial/ethnic minority populations in the U.S. are less likely to utilize hospice services nearing their end of life, potentially diminishing their quality of care while also increasing medical costs. Qualitative surveys were conducted with 41 hospices across the U.S. Two key themes emerged regarding hospices that reported relatively successful outreach to racial/ethnic minority populations. First, hospices often incorporated a culture of inclusivity, which included forming committees, offering language resources to patients and providing cultural training to staff. Second, hospices often built strong external relationships outside of the medical care silo with trusted members of the minority communities. Hospices which adopted a culture of inclusivity that appeared to permeate throughout their business systems and practices consistently reported that such efforts made it more likely for racial/ethnic minorities to use their hospice services. A culture of inclusivity often included forming a committee focused specifically on goals related to equity and anti-discrimination. An important role these committees could play is to provide standardized evaluation processes for their inclusion and outreach programs, as suggested by related research. Given the scarcity of hospice resources, it is paramount to understand whether various approaches used to improve minority care and utilization are effective. This study suggests that committees specifically geared toward inclusivity practice are often deemed successful by hospice leaders and thus warrant further quantitative studies in terms of overall effectiveness. **Full text:** <https://bit.ly/2A17zSX>

Noted in Media Watch 17 February 2020 (#653, p.5):

- *AMERICAN JOURNAL OF MANAGED CARE* | Online – 11 February 2020 – ‘**Racial and ethnic disparity in palliative care and hospice use.**’ This study provides new evidence regarding racial and ethnic differences in the use of inpatient palliative care (PC) consultations and hospice care within a large urban population, as well as the relationship between the receipt of an inpatient PC consultation and hospice enrollment. The results of the multivariable analyses indicate that African American patients were more likely to receive an inpatient PC consultation in the final hospital stay compared with white patients, before controlling for hospital site, whereas there were no differences in inpatient PC consultation use between white and Hispanic patients. **Full text:** <http://bit.ly/3bCBDCL>

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Noted in Media Watch 8 July 2019 (#621, p.7):

- *GERONTOLOGY & GERIATRIC MEDICINE* | Online – 27 June 2019 – ‘**Closing the gap in hospice utilization for the minority Medicare population.**’ The average *per capita* end-of-life medical spending in the last year of life is \$80,000, comprising a larger fraction of its gross domestic product than that for all eight other countries examined in a 2017 study.¹ With the potential to provide nearly \$270 million in annual cost savings while also improving health outcomes, research on specific programs that successfully reduce the racial/ethnic minority hospice enrollment gap is paramount. Collaboration between hospices, health systems and community organizations is needed to reduce the disparities between racial/ethnic minority and White Medicare beneficiary hospice utilization. **Abstract:** <http://bit.ly/307JL Vf>
- 1. ‘End-of-life medical spending in last twelve months of life is lower than previously reported,’ *Health Affairs*, 2017;36(7):1211-1217. [Noted in 10 July 2017 issue of Media Watch (#520, p.10)] **Full text:** <http://bit.ly/2XhOpOy>
- *JOURNAL OF RACIAL & ETHNIC HEALTH DISPARITIES* | Online – 27 June 2019 – ‘**Integrating palliative care into the chronic illness continuum: A conceptual model for minority populations.**’ The goal of the conceptual model is to provide a roadmap for healthcare professionals to use when designing, implementing, managing, and/or evaluating palliative care (PC) services for chronically ill minority Americans. A literature review demonstrated that minority patients benefitted the most from culturally tailored, systematic interventions (such as advanced care planning education) in all phases of PC, which led to increases in advance directive completion, better symptom control, and hospice utilization. **Abstract (w. list of references):** <http://bit.ly/2YknMtn>

Perspectives of Nunavut patients and families on their cancer and end-of-life care experiences

INTERNATIONAL JOURNAL OF CIRCUMPOLAR HEALTH | Online – 25 May 2020 – This study arose from a recognition among service providers that Nunavut patients and families could be better supported during their care journeys by improved understanding of people’s experiences of the healthcare system. Using a summative approach to content analysis informed by the Piliriqatigiinniq Model for Community Health Research, the authors conducted in-depth interviews with 10 patients and family members living in Nunavut communities who experienced cancer or end-of-life care. Results included the following themes: difficulties associated with extensive medical travel; preference for care within the community and for family involvement in care; challenges with communication; challenges with culturally appropriate care; and, the value of service providers with strong ties to the community. These themes emphasise the importance of health service capacity building in Nunavut with emphasis on Inuit language and cultural knowledge. They also underscore efforts to improve the quality and consistency of communication among health service providers working in both community and southern referral settings and between service providers and the patients and families they serve. **Full text:** <https://bit.ly/2zm8A89>

N.B. Translated, piliriqatigiinniq means “working in a collaborative way for the common good.” Piliriqatigiinniq Model for Community Health Research: <https://bit.ly/3gImS9A>

Noted in Media Watch 25 November 2029 (#651, p.10):

- *CANADIAN JOURNAL ON AGING* | Online – 20 November 2019 – “**Nothing about us, without us.**”: **How community-based participatory research methods were adapted in an Indigenous end-of-life study using previously collected data.**’ The authors describe how their research team of academic researchers and a national Indigenous health organization adapted community-based participatory research (CBPR) methods in a research project using previously collected data to examine end-of-life healthcare service delivery gaps for Indigenous people in Ontario. They describe the process of how they developed their research partnership and how grounding principles and Indigenous ways of knowing guided their work together. **Abstract (w. list of references):** <http://bit.ly/347QmRY>

N.B. Selected articles on palliative and end-of-life care for the Indigenous peoples of Canada noted in 11 November 2019 issue of Media Watch (#639, pp.1-2).

Living in the moment for people approaching the end of life: A concept analysis

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – Accessed 26 May 2020 – The purpose of this analysis was to generate a clear definition for improving dignity-conserving care and facilitate further interventions for such care in end-of-life (EoL) care settings. A focus of EoL care is to help patients die with dignity. The literature reports that patients at the EoL fear the loss of dignity. Dignity-conserving care, therefore, is essential for supporting these patients and their families... The results of this study show that living in the moment is considered to be an effective coping strategy for dignity-conserving care. Patients who live with a life-threatening illness who are living in the moment report that simple pleasures enrich their limited life. Examples are listening to music, gardening, reading a newspaper, looking out of a window, building a shed, playing cards, fixing the back patio or viewing nature from indoors. It is also important to relieve symptoms like pain and anxiety for people who have a life-threatening illness. The researchers in the reviewed literature highlight that having conversations with patients about their hobbies or daily lives may enhance their capacity to live in the moment. In addition ... prioritising relationships, living life to the fullest, maintaining normality and not worrying about the future are all fundamental attitudes for living in the moment in people at the EoL. The existing body of research supports the notion that discussing with these patients the most important things in their lives helps them find meaning in life and to live in the moment. Talking with them about issues that are non-illness related, encouraging them to partake in various activities (as appropriate), supporting them with carrying out their daily routines, and helping them set realistic goals are also important for enabling them to live in the moment. **Full text:** <https://bit.ly/2yDruXI>

Palliative care consultation reduces heart failure transitions: A matched analysis

JOURNAL OF THE AMERICAN HEART ASSOCIATION | Online – 27 May 2020 – Palliative care is one additional service cardiologists can use in their comprehensive management of patients with heart failure (HF). The observed association with reduced rehospitalization within 6 months among patients who received PC provides additional support that a palliative approach may be used to help guide goals-of-care conversations with patients living with HF. Also, engagement of PC during hospitalization may build an ongoing relationship that increases PC and facilitates discussion during subsequent hospitalizations or outpatient visits. Prior evidence suggests that PC might reduce healthcare costs. When allowed, PC may be used concurrently with curative, life-preserving treatment. Importantly, PC is not universally available. In this study, the authors found a wide variability in the PC encounters for patients hospitalized with HF among medical centers. They postulate that PC is underutilized in part because of the misconception that it is synonymous with hospice. **Full text:** <https://bit.ly/2Abxlys>

N.B. Additional articles on palliative care for people living with HF noted in 18 May 2020 issue of Media Watch (#666, pp.9-10)]

Related:

- *HEART* | Online – 22 May 2020 – ‘**Palliative care in cardiology: Knowing our patients’ values and responding to their needs.**’ Palliative care (PC) is a specialised type of medical care that focuses on improving communication about goals-of-care (GoC), maximising quality of life and reducing symptoms. It is patient-centred and family-centred care that is appropriate at any age and at any stage of a serious illness. In the past, it was often used synonymously with hospice, particularly in end-stage cancer, and gained a reputation as “doing nothing” or “giving up.” However, PC is better seen as an “interventional” specialty because of its focus on GoC that frame the appropriateness of therapies and its use of measures to ameliorate suffering. **Introduction:** <https://bit.ly/36sBSOp>



Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.21.

Improper drug disposal after patients on home hospice care die

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2020;323(20):1998. Patients who die while receiving hospice care at home often leave behind unused controlled substances that aren't disposed of properly and could be diverted or misused, according to a recent U.S. Government Accountability Office (GAO).¹ Most patients receiving hospice care are at home, and they are often prescribed opioids for pain and central nervous system depressants for anxiety or sleep disorders. A 2018 federal law that addresses opioid overdoses allows employees of qualified hospice programs to collect and destroy controlled substances after patients die at home. Some states had laws before the federal legislation was enacted that allowed hospice employees to dispose of unused controlled substances. The GAO interviewed officials from 7 Medicare-certified hospices and from 16 hospice and nurse trade associations. Three of the hospices were in states without laws about disposing patients' unused medications. Representatives of two hospices said they began collecting and destroying unused controlled substances after the federal law's passage, but an official of the third hospice said the state health department had instructed it to leave controlled substances in patients' homes until a state law was enacted. That hospice continued to teach family members how to dispose of medications. Hospice and state hospice association officials said disposing controlled substances in patients' homes can be time-consuming and expensive, and family members and caregivers sometimes object. **Full text:** <https://bit.ly/2ZCjaCr>

1. 'Preventing Drug Diversion: Disposal of Controlled Substances in Home Hospice Settings,' U.S. Government Accountability Office, April 2020. [Noted in 20 April 2020 issue of Media Watch (#662, p.3)]
Download/view at: <https://bit.ly/2yIO5av>

Noted in Media Watch 17 February 2020 (#653, p.10):

- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2020;323(6):566-568. '**Estimates of medication diversion in hospice.**' Given the challenges of symptom management during hospice care, patients require responsive opioid prescribing. Within the context of the national opioid crisis, medication diversion in hospice is an increasing concern. The authors conducted a national survey of hospices (June-September 2018). Using 2015 data on U.S. hospices, they randomly selected 600 agencies, proportionately stratified by state and profit status. The authors surveyed agency representatives by phone or online about practices, policies, and experiences regarding medication diversion.
Abstract: <http://bit.ly/2uAETxu>

N.B. Additional articles on medication diversion in hospices noted in 13 January 2020 issue of Media Watch (#648, p.5).

Does the International Narcotics Control Board sufficiently prioritise enablement of access to therapeutic opioids? A systematic critical analysis of six INCB annual reports, 1968-2018

JOURNAL OF GLOBAL HEALTH REPORTS | Online – 29 May 2020 – The International Narcotics Control Board (INCB) has overseen international drug control since 1968 with the dual remit of restricting illicit production and use of controlled substances, whilst enabling access for clinical purposes. Two opioid crises are present under its jurisdiction: 1) Abuse, dependence and premature mortality in high-income countries; and, 2) inadequate supply of opioids for clinical purposes for most of the world represented almost exclusively by low- and middle-income countries. In INCB Annual Reports since 1968, prioritisation has been given to the restriction of production, trade and use of controlled substances for illicit use over promoting therapeutic opioids. Urgent international and national action is required to improve methods of accurately estimating population-level needs for therapeutic opioids for all clinical requirements. From there, health systems will have accurate assessments of the extent to which reform is needed to ensure that "needs" and "requirements" for therapeutic opioids become equivalent. Fears of illicit production or use should not limit the prospects of accessing appropriate therapeutic opioids where the majority of the world, today, have no realistic access. Patients the world over and their families deserve better.
Full text: <https://bit.ly/2ZRwIQj>

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Noted in Media Watch 23 May 2020 (#658, p.7):

- *CURRENT ONCOLOGY REPORTS* | Online – 13 March 2020 – ‘**Stringent control of opioids: Sound public health measures, but a step too far in palliative care?**’ Opioids are the only class of drug with the proven ability to control severe pain. The introduction of stringent opioid prescribing restrictions has inevitably impacted upon the ability of those prescribing opioids for advanced life-limited disease to practice as previously and could limit the supply of adequate pain relief to patients with cancer. This review considers the evidence that symptom management of patients with advanced cancer contributes to the “opioid problem” and whether there is adequate recognition of the risks involved. **Abstract (w. list of references):** <http://bit.ly/2w7Ltwj>

Noted in Media Watch 30 December 2019 (#646, p.11):

- *PALLIATIVE MEDICINE* | Online – 23 December 2019 – ‘**The perception of barriers concerning opioid medicines: A survey examining differences between policy makers, healthcare professionals and other stakeholders.**’ There are significant differences in the perception of barriers between policymakers and healthcare professionals working in the field of harm reduction, pain management and palliative care... The aspects that were most frequently perceived as a major barrier or as having major impact were lack of training, lack of financial resources, and physicians’ reluctance to prescribe opioids. The responses to the knowledge and attitude questions mirror familiarity with specific professional discourses in the diverse stakeholder groups. **Full text:** <http://bit.ly/34RxB4A>

Noted in Media Watch 10 June 2019 (#617, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2019;22(6):612-614. ‘**That was then, this is now: Using palliative care principles to guide opioid prescribing.**’ Palliative care (PC) providers ... do not want to contribute to the growing problem of opioid misuse, overdose, and accidental death. So the question becomes how do we balance the important goal of reducing suffering with our equally compelling desire to act as responsible providers. Consensus-based PC principles may serve as a clinically useful guide to the decision-making process about whether or not to prescribe opioids. The approach using these familiar core principles is probably best illustrated by the following two patients ... and their complex pain management issues. **Full text:** <http://bit.ly/2KnWQVL>

A realist evaluation of a “single point of contact” end-of-life care service

JOURNAL OF HEALTH ORGANIZATION & MANAGEMENT | Online – 25 May 2020 – Following the development of a service that consisted of a “single point of contact” to coordinate end-of-life care (EoLC), including EoLC facilitators and an urgent response team, the authors explored whether the provision of coordinated EoLC would support patients being cared for or dying in their preferred place and avoid unwanted hospital admissions. Advance care planning (ACP) increased through the first three years of the service (from 45% to 83%) and on average 74% of patients achieved preferred place of death. More than 70% of patients avoided an emergency or unplanned hospital admission in their last month of life. The mechanisms and context identified as driving forces of the service included: 7/7 single point of contact; coordinating services across providers; recruiting and developing the workforce; understanding and clarifying new roles; and, managing expectations. This paper provides an evaluation of a novel approach to EoLC and creates a set of hypotheses that could be further tested in similar services in the future. **Abstract:** <https://bit.ly/36uAZ8b>

Complexities and constraints in end-of-life care for hospitalised prisoner patients

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 24 May 2020 – Managing the care of an increasing and ageing prisoner population, including providing palliative and end-of-life (EoL) care, is a challenge worldwide. There is little known about the views of health professionals who provide palliative care (PC) to hospitalised prisoner patients. A qualitative study was undertaken involving semi-structured focus groups and interviews with 54 medical, nursing and allied health staff engaged in the care of hospitalised prisoner patients. Purposive sampling from a metropolitan teaching hospital responsible for provid-

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ing secondary and tertiary healthcare for prisoners in Victoria, Australia, for 40-years was utilised to identify and seek perspectives of staff from a variety of clinical disciplines. Participants in this study described significant constraints in how they provide PC to hospitalised prisoners. Key themes emerged describing constraints on: prisoner health decisions; provision and place of care; patient advocacy; and, how care is delivered in the last days of life. Participants highlighted a deep philosophical tension between prison constraints and the foundational principles of PC. Clarity of correctional services processes, protocols, and aspects of security and related training for health professionals is needed to ensure improved care for prisoners with progressive and life-limiting illness. Further research is required to seek the views of prisoners facing EoL and their families. **Abstract (w. link to references):** <https://bit.ly/2ZBnOk3>

N.B. EoL 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>

Palliative care utilization among patients with COVID-19 in an underserved population: A single-center retrospective study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 23 May 2020 – There was a low utilization rate of palliative care (PC) in patients with COVID-19. This can be due to the hostile atmosphere created by the pandemic, infection control measures, and extreme pressure on services. Evidence has shown that growing healthcare demands in the setting of COVID-19 has overwhelmed and overburdened the capacity of U.S. hospitals. In that context, most hospital resources were allocated toward direct patient care with some services prioritized over others. However, provision of relief from suffering, support in complex decision making, and management of clinical uncertainty, as the foundational features of PC, should be essential responses to the pandemic crisis. Addressing patients' and families' sufferings, and supporting their decision making in clinical uncertainty are as important as medical management since there is still no definitive treatment for COVID-19. The standard humanitarian response in this pandemic crisis should be re-imagined encompassing both saving lives and minimizing suffering. Palliative trained specialists deliver holistic care by ensuring symptom management and psychological support to both patients and their families. Even though critical care physicians and hospitalists can render some degree of palliative services, they are already overburdened with their increased workloads, hence making PC services indeed invaluable. **Full text:** <https://bit.ly/36qJwc5>

Related:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 May 2020 – **'Can video consultations replace face-to-face interviews? Palliative medicine and the COVID-19 pandemic: Rapid review.'** Although video consultations (VC) cannot fully replace face-to-face encounters, they may radically reduce the need, so combating the risk of spreading COVID-19... While VC for palliative care in the U.K. will be a radical change in service delivery, the international evidence appears to support it as effective, accessible, acceptable and cost-effective. Importantly, patients and relatives report VC to be highly acceptable and often wish it had been offered sooner. The principle concern from health professionals is most notably in relation to the confidentiality and security of the VC. **Full text:** <https://bit.ly/2X93Com>
- *JOURNAL OF CLINICAL ETHICS*, 2020;31(2):RP97-RP-99. **'Compassionate communication and end-of-life care for critically ill patients with SARS-Cov-2 infectio.'** Public health strategies recommend isolating patients with SARS-CoV-2 infection. But compassionate care in the intensive care unit (ICU) is an ethical obligation of modern medicine that cannot be justified by the risk of infection or the lack of personal protective equipment. This article describes the experiences of clinicians in ICUs in the south of Spain promoted by the Andalusian Society of Intensive Care SAMIUC, in the hope it will serve to improve the conditions in which these patients die, and to help their families who suffer when they cannot say goodbye to their loved ones. **Full text (download/view at):** <http://bit.ly/2FpPSLx>

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- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 29 May 2020 – ‘**National outreach of telepalliative medicine volunteers for a New York City safety net system COVID-19 pandemic response.**’ The authors successfully implemented a telepalliative medicine response within a large safety-net system without a pre-existing telehealth infrastructure. Within just 72 hours of the initial outreach, over 400 volunteers enlisted, reflecting a rapid and robust response. To the authors’ knowledge, this is the first model to leverage external telepalliative medicine volunteers from across the country for an institutional COVID-19 pandemic response. Several concepts resonated through our process, which may aid other institutions in future efforts. **Full text:** <https://bit.ly/3qtEUXn>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 May 2020 – ‘**Development of a palliative care toolkit for the COVID-19 pandemic.**’ A workgroup of interdisciplinary palliative care (PC) clinicians developed the toolkit, consisting of a detailed chapter in a COVID-19 online resource, a mobile and desktop web application, one-page guides, pocket cards and communication skills training videos. These provide expert, evidence-based guidance on symptom management ... and also on serious illness communication, including conversations about goals of care, code status, and end-of-life. Also created was a nurse resource hotline staffed by PC nurse practitioners and virtual office hours staffed by a PC attending physician. **Full text:** <https://bit.ly/2XpPHcj>
- *PEDIATRICS* | Online – 26 May 2020 – ‘**Pediatric palliative care in a pandemic: Role obligations, moral distress, and the care you can give.**’ Many ethical issues arise concerning care of critically ill and dying patients during the COVID-19 pandemic. The authors present two cases that highlight two different sorts of ethical issues. One is focused on the decisions that have to be made when the surge of patients with respiratory failure overwhelm ICUs. The other on the psychological issues that arise for parents who are caring for a dying child when infection-control policies limit the number of visitors. Both raise challenges for caregivers who are trying to be honest, to deal with their own moral distress, and to provide compassionate palliative care. **Full text (click on pdf icon)** <https://bit.ly/3d7X2E4>
- *PROFESSIONAL CASE MANAGEMENT* | Online – 20 May 2020 – ‘**End-of-life care, workers’ compensation case management, legal and ethical obligations, remote practice, and resilience.**’ The COVID-19 global pandemic has resulted in a crisis case managers and other healthcare professionals never faced something like it before. At the same time, it has provided opportunities for innovation and creativity including use of digital and telecommunication technology in new ways to ensure the continued delivery of health and human services to those who need them regardless of location. It has also resulted in the development of necessary and impactful partnerships within and across different healthcare organizations and diverse professional disciplines. **Abstract:** <https://bit.ly/2ywKiro>

Family conferences in prenatal palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 June 2020 – Fetal malformations are diagnosed prenatally in nearly 3% of pregnancies, and ~1.2% are major malformations. After prenatal diagnosis, it is imperative to consider families’ values and to support their decision-making process. Prenatal palliative care (PC) is a growing field mainly based on family conferences. The prenatal care setting is unique and differs from postnatal and adult care. There are no descriptions of family conferences in prenatal PC. The descriptions of themes that emerge from prenatal care conference charts may guide professionals in this delicate task, and help determine the causes of suffering and identify family values before the birth of the infant. This analysis may guide health professionals who seek to better identify family needs and values and organize follow-up during prenatal PC. **Abstract:** <https://bit.ly/36HcZPc>

Noted in Media Watch 13 April 2020 (#661, p.10):

- *OBSTETRICS, GYNECOLOGY & REPRODUCTION*, 2020;14(1):80-88. ‘**A child’s right to receive pediatric palliative care at prenatal stage.**’ The issue of the right of such a child to palliative medical care theoretically and, especially, practically is not studied. The authors outline the essence, nature as well as range of child’s guarantees for receiving pediatric palliative care (PC) at prenatal stage including common scope of the rights for such patients. It is emphasized that a child at prenatal stage (starting from certain age) is able to feel pain sensation and suffer from it, thereby underlying its right for PC. It is underscored as to why a child’s right at prenatal stage for pediatric PC (if necessary) is subject to legal recognition and legal protection. **Full text (click on pdf icon):** <https://bit.ly/2UQ9yS0>

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Noted in Media Watch 10 August 2015 (#422, p.8):

- *AMERICAN JOURNAL OF MATERNAL CHILD NURSING*, 2015;40(1):44-50. '**Clinician perspectives of barriers in perinatal palliative care.**' Physicians and nurses [i.e., study participants] differ significantly in the barriers they report. Nurses expressed more obstacles at the healthcare systems level reporting difficulty in their ability to garner interdisciplinary support and gain administrative backing. Physicians are more confident in their ability to counsel patients than nurses. Members of both disciplines express similar feelings of distress and helplessness when caring for families expecting a fetal or neonatal demise. They also report a lack of societal support and understanding about perinatal palliative care. **Abstract:** <https://bit.ly/3e3Gpu4>

Integration of routine parental request of organ donation in end-of-life care of children with neurologic disorders in the U.K.: Unresolved medical, legal, cultural, and religious challenges

NEUROCRITICAL CARE | Online – 22 May 2020 – The integration of routine referral of all children with severe neurologic disorders for potential end-of-life (EoL) organ donation ignores contemporary medical, legal, cultural, and religious challenges in the U.K. This underscores that healthcare professionals have ethical and legal obligations to be fully transparent and non-biased in disclosure of all relevant information when discussing donation to ensure informed parental decision-making. It is recommended that: 1) Practice guidelines for the diagnosis and treatment of neurologic disorders following severe brain injuries in children are updated and aligned with recent advances in neuroscience to avoid potential errors from premature treatment discontinuation and/or incorrect diagnosis of death by brain(stem) criteria" and, 2) A transparent societal dialogue is commenced to address the legal, cultural, and religious consequences of routine integration of organ donation in EoL care of children. If the contemporary challenges are resolved appropriately and donation discussions are fully transparent and non-biased with decision-makers, referral for donation in EoL care is less likely to harm children and parents. **Full text:** <https://bit.ly/3c2ak3m>

Nursing competencies across different levels of palliative care provision: A systematic integrative review with thematic synthesis

PALLIATIVE MEDICINE | Online – 26 May 2020 – Palliative care (PC) exists in diverse healthcare settings. Nurses play a crucial role in its provision. Different levels of PC provision and education have been recognized in the literature. Therefore, nurses need a set of various competencies to provide high-quality PC. A total of 7,454 articles were retrieved, 21 articles were included in the analysis. Six diverse nursing competencies dimensions, namely leadership, communication, collaboration, clinical, ethico-legal and psycho-social and spiritual were identified. The reports rarely defined the level of PC and covered a wide array of healthcare settings. Nurses need a wide range of competencies to provide quality PC. Few studies focused on which competencies are relevant to a specific level of PC. Further research is needed to systematize the nursing competencies and define which nursing competencies are central for different levels of PC to enhance PC development, education and practice. **Abstract (w. list of references):** <https://bit.ly/2ZHkfJh>

Noted in Media Watch 4 November 2019 (#638, p.14):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(5):390-396. '**Guiding the process of dying: The personal impact on nurses.**' Some of the most ethically challenging and emotionally demanding aspects of nursing occur in caring for patients and their family at the end of life. The aims of this study were to examine the views of acute care nurses caring for patients during transition to comfort care, to describe the personal impact on nurses, and to identify nurses' strategies for self-support and development of competence. Participants experienced moral distress in situations of continuing treatment when a cure was unlikely. In managing symptoms for patients, they struggled to foster an often-tenuous balance of patient comfort and calm without over-sedation. **Abstract:** <http://bit.ly/2JoGillo>

Global development of children's palliative care: The picture in 2017

WELLCOME OPEN RESEARCH | Inprint – 20 May 2020 – The authors were able to identify a total of just 21 countries in the highest categories of development for children's palliative care (PC); these countries contain 232 million children and young people age 19 and under (9.2% of the global total). In addition, 778 million children (30.7%) live in 55 countries with only isolated and patchy provision. Meanwhile, 610 million children (24.1%) live in 77 countries that only have capacity building activity in place. A further 265 million children (10.4%) live in 106 countries where no known children's PC activity is taking place, or it has proved impossible to gather any evidence on it. An even greater number, 646 million children (25.5%), live in 29 countries where the available evidence on the level of children's PC development is contradictory. Accordingly, less than 10% of those under 20 years old live in countries where PC for children is of the highest current standards. Almost a third of children live in countries where such care is highly limited in provision, and incommensurate with need. One quarter of all children live in countries that are only beginning to mobilise efforts for children's PC. The rest live in countries where it is proving difficult even to assess available levels of children's PC. The authors have previously shown that the overall development of PC, despite some gains over time, is incapable of meeting existing need. For the world's children who could benefit from PC, the situation is even more serious and requires a global intervention of massive scale for its rectification. **Full text:** <https://bit.ly/3ggncq5>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- **MORTALITY** | Online – 29 May 2020 – '**Assisted dying in New Zealand: what is known about the values underpinning citizens' positions?**' In New Zealand ... the introduction of a third Bill on assisted dying to the House of Representatives following a high profile court case, afforded an opportunity for examining how assisted dying is discussed in the public sphere. Social media postings include the voices of citizens who may not participate in formal public consultation processes. Contributors' posts reveal deeply held socio-cultural values, as well as tensions about the relationship between citizens and the apparatus of government. In this article, we report on a discourse analysis of a selection of social media postings to illustrate the values that underpin the positions taken by contributors to these fora. These illustrate what many New Zealand citizens perceive to be at stake. The social media debate over how we should die reveals deeper issues about the nature of the society we want to live in, and the relationship between the State and citizens. **Abstracts:** <https://bit.ly/3gyZbKW>

Mapping global palliative care development

For more than a decade, a series of studies has monitored the level of palliative care (PC) development in all the countries of the world...^{1,2,3} These studies have contributed significantly to advocacy, planning and monitoring for the improvement of PC worldwide. They have also sought progressively to develop more robust methods for measuring the country-level status of PC provision, through continuing identification and refinement of the appropriate indicators. The first study allocated each country to one of four categories of development, using data synthesised from a variety of academic, professional and 'grey' literature, with expert opinion used as a substitute where necessary. The second study used a refined six category classification and was based on the identification of in-country experts or "champions" who were asked for their opinion on their country's level of development. The most recent iteration of the study develops the method further, again using six categories of development, but now with more detailed information gathered from a survey of national experts across 198 countries, and based on a set of 10 PC indicators derived from the literature.

1. 'Mapping levels of palliative care development: A global view,' *Journal of Pain & Symptom Management*, 2008; 35(5):469-485. **Full text:** <http://bit.ly/2Gplge6>
2. 'Mapping levels of palliative care development: A global update,' *Journal of Pain & Symptom Management*, 2013;45(6):1094-1106. [Noted in 1 October 2012 issue of Media Watch (#273, p.11)] **Full text:** <https://bit.ly/3bWpYxd>
3. 'Mapping levels of palliative care development in 198 countries: The situation in 2017,' *Journal of Pain & Symptom Management*, 2020;59(4):794-807. [Noted in 9 December 2019 issue of Media Watch (#643, p.2)] **Full text:** <http://bit.ly/2s1eAin>

Cont.

- *RECENTI PROGRESSI IN MEDICINA*, 2020;111(5):316-326. **‘Medical assistance in dying: Just an ethical or legal issue?’** According to current vital statistics suicide appears as a growing public health problem in most Western countries. However, suicide is rarely discussed in scientific journals, possibly because of a persisting moral stigma. As a consequence, the diverse bases of suicidal behavior are little understood while the role of chronic-degenerative terminal diseases (CDTD) has been poorly investigated. In the present study, the topic of suicidality was addressed in a clinical, holistic, perspective in an attempt to clarify how, in some chronically ill patients, the decision to end their own life is taken independently from mental disorders, being conversely, the expression of a rational psychological pattern which copes with the burden of chronic illnesses to become an integral part of their clinical spectrum. An assisted suicide request should therefore be considered from a clinical point of view and not only as an ethical or legal issue, in fact a holistic evaluation of the patient’s situation must be performed, conferring the decisions making process a further in-depth line of thinking. In this study, the authors first examined the relationship between suicide and CDTD as reported in the medical literature; then they reviewed the psychological theories which allegedly explain suicidal behavior; finally, the authors discuss the possible role of a full-fledged palliative care in preventing suicide and in managing death requests by CDTD patients. **Abstract:** <https://bit.ly/3egvnlk>

N.B. Italian language article.

[Publishing Matters](#)

A methodological review of mixed methods research in palliative and end-of-life care (2014-2019)

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 29 May 2020 – Mixed methods research has been increasingly recognized as a useful approach for describing and explaining complex issues in palliative care (PC) and end-of-life research. However, little is known about the use of this methodology in the field and the ways in which mixed methods studies have been reported. The purpose of this methodological review was to examine the characteristics, methodological features and reporting quality of mixed methods articles published in PC research. The authors screened all articles published in eight journals specialized in PC between January 2014 and April 2019.¹ Those that reported a mixed methods study were included. The Good Reporting of a Mixed Methods Study criteria were used to assess reporting quality. Findings showed that 57.9% of the identified studies used a convergent design and 82.4% mentioned complementarity as their main purpose for using a mixed methods approach. The reporting quality of the articles generally showed a need for improvement as authors usually did not describe the type of mixed methods design used and provided little detail on the integration of quantitative and qualitative methods. Based on the findings, recommendations are made to improve the quality of reporting of mixed methods articles in PC. **Full text:** <https://bit.ly/2TQNiGN>

1. *Palliative Medicine, Journal of Palliative Medicine, BMJ Supportive & Palliative Care, BMC Palliative Care, American Journal of Hospice & Palliative Medicine, Journal of Palliative Care, Journal of Hospice & Palliative Nursing, and Palliative & Supportive Care.*

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Cont.

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