

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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Until the GP role in palliative care (PC) is clarified along with the domains and processes that fall within the GP's remit, there seems little benefit to discussions of how to assess GP competence in providing PC.

'Bolstering general practitioner palliative care: A critical review of support provided by Australian guidelines for life-limiting chronic conditions' (p.5), in *Healthcare*.

Important notices: 1) The next issue of Media Watch will be published 4 January 2021; and, please note a change in my email address: BarryRAshpole@bell.net. BRA

Educating the News Media About Palliative care

Covering stories about palliative care: Four tips for journalists

JOURNALIST'S RESOURCE | Online – 14 December 2020 – The **COVID-19** pandemic has brought a surging demand for palliative care (PC) clinicians to help care for critically ill patients in hospital emergency rooms across the U.S. PC is a subspecialty of medicine that focuses on treating seriously ill patients to maximize their quality of life by providing relief from pain, stress and other symptoms. Historically, PC specialists don't typically work in emergency rooms. However, these clinicians are experts in having "goals-of-care" conversations, which have become crucial in emergency rooms overwhelmed with COVID-19 patients. In a goals-of-care conversation, clinicians talk to the patient or family members about their medical situation and ask questions about what kind of care the patient would want if they get sicker with COVID-19. One COVID-19 era study showed that many elderly patients who are critically ill with the virus do not want aggressive life-sustaining measures, including into-

bation and CPR.¹ A goals-of-care conversation allows patients to have a voice in their own care and prevents them from enduring aggressive medical interventions that are incompatible with their wishes and values. Here are several tips for reporting stories about PC, based on conversations with Dr. Vicki Jackson, chief of the Division of Palliative Care at Massachusetts General Hospital and Dr. Diane Meier, director of the Center to Advance Palliative Care, based at the Icahn School of Medicine at Mount Sinai Hospital in New York. <http://bit.ly/3mlmVE7>

Specialist Publications

'A virtual community of practice to improve palliative care knowledge and self-efficacy among inter-professional healthcare providers' (p.7), in *Journal of Palliative Medicine*.

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1. 'Early intervention of palliative care in the emergency department during the COVID-19 pandemic,' JAMA Internal Medicine, published online 5 June 2020. [Noted in Media Watch 8 June 2020 (#669, p.11)] **Full text:** <https://bit.ly/2Y7eFgS>

N.B. For journalists covering the topic of PC, *Journalist's Resource* curated and summarized several studies relevant to PC during COVID-19: <http://bit.ly/3nksd0Y>

Specialist Publications

Palliative care in emergency general surgery patients: Reduced inpatient mortality and increased discharge to hospice

THE AMERICAN SURGEON | Online – 14 December 2020 – Admissions due to emergency general surgery (EGS) are on the rise, and patients who undergo emergency surgery are at increased risk of mortality. The authors hypothesized that utilization of palliative care (PC) and discharge to hospice in the EGS population have increased over time and that this is associated with a decrease in inpatient mortality. Of the patients included in this study .3% received PC and .2% were discharged to hospice. Over time, rates of PC and hospice discharge increased while inpatient mortality decreased. In the 4% of patients with "extreme likelihood of dying," 3% received PC, 5% were transitioned to hospice care, and 22% suffered inpatient mortality. Controlling for patient characteristics, utilization of PC services was associated with increased odds of discharge

to hospice compared to inpatient mortality. Despite the known increased risks associated with emergency surgical diagnoses, PC services remain infrequently utilized in the EGS population. This may be an opportunity for lessening suffering, improving patient-concordant care and outcomes, and reducing non-beneficial and unwanted care. **Abstract (w. list of references):** <http://bit.ly/3qS6NgO>

Publishing Matters

'Changes in medical scientific publication associated with the COVID-19 pandemic' (p.12), in *Medical Journal of Australia*.

N.B. Additional articles on integrating primary and specialty PC into surgical practice noted in Media Watch 30 November 2020 (#694, pp.5-6).

A conscious choice: Is it ethical to aim for unconsciousness at the end of life?

BIOETHICS | Online – 17 December 2020 – One of the most commonly referenced ethical principles when it comes to the management of dying patients is the doctrine of double effect (DDE). The DDE affirms that it is acceptable to cause side effects (e.g., respiratory depression) as a consequence of symptom-focused treatment. Much discussion of the ethics of end of life care (EoLC) focuses on the question of whether actions (or omissions) would hasten (or cause) death, and whether that is permissible. However, there is a separate question about the permissibility of hastening or causing unconsciousness in dying patients. Some authors have argued that the DDE would not permit EoLC that directly aims to render the patient unconscious. The claim is that consciousness is an objective human good and therefore doctors should not intentionally (and permanently) suppress it. Three types of EoLC practices are explored in this article: symptom-based management (e.g., analgesia); proportional terminal sedation as a means of relieving suffering (also referred to as palliative sedation or continuous deep sedation); and, deliberate and rapid sedation to unconsciousness until death... After examining the common arguments for the various types of symptom-based management and sedation, the authors apply the DDE to the latter two types of EoLC practices. They argue that aiming at unconsciousness, contrary to some claims, can be morally good or at least morally neutral in some dying patients. **Full text:** <https://bit.ly/3apg2iW>



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Saving the most lives: A comparison of European triage guidelines in the context of the COVID-19 pandemic

BIOETHICS | Online – 16 December 2020 – In March 2020, the rapid increase in severe COVID-19 cases overwhelmed the healthcare systems in several European countries. The capacities for artificial ventilation in intensive care units were too scarce to care for patients with acute respiratory disorder connected to the disease. Several professional associations published COVID-19 triage recommendations in an extremely short time: in 21 days between 6 March and 27 March. In this article, the authors compare recommendations from five European countries [i.e., Austria, Belgium, Germany, Italy and Switzerland], which combine medical and ethical reflections on this situation in some detail. The authors' aim is to provide a detailed overview on the ethical elements of the recommendations, the differences between them and their coherence. In more general terms they want to identify shortcomings in regard to a common European response to the current situation. **Full text:** <https://bit.ly/2KdE85g>

Extract from *Bioethics* article

It is highlighted by the Italian and Austrian text that withholding maximal intensive treatment ... does not automatically preclude other alternatives such as non-invasive ventilatory support if appropriate. Other statements are mute on the question of second-best treatments. Apart from the Belgian text, all documents consider palliative care (PC) strategies for dying patients, which is also subject to a wider international discussion. The German recommendations stress that PC must always be guaranteed for patients. The Italian, Austrian and Swiss documents also stress the need to provide appropriate PC after triage according to professional standards. As for constant (re-)assessment of the patient in admission, as well as during their stay in the ICU, the Swiss recommendation repeatedly recalls the need for a comprehensive PC plan as the final treatment for patients if intensive care is not appropriate (anymore).

Noted in te Media Watch 27 July 2020 (#676, p.4):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 21 July 2020 – “**Palliative pandemic plan**”: **Triage and symptoms algorithm as a strategy to decrease providers' exposure, while trying to increase teams availability and guidance for goals of care and symptoms control.** The authors' formulated a two-team approach which includes triage algorithms for palliative consults as well as acute symptomatic management for both patients diagnosed with or under investigation for COVID-19. These algorithms provided a delineated set of guidelines to triage patients in need of palliative services and included provisions for acute symptoms management and the protection of both the patient care team and the families of patients with COVID-19. **Full text:** <https://bit.ly/32GfVel>

Noted in Media Watch 6 July 2020 (#673, p.7):

- *THE HASTINGS REPORT*, 2020;50(3):71-72. ‘**Avoiding ineffective end-of-life care: A lesson from triage.**’ Many healthcare workers have noticed that, outside the pandemic shortage situation, we routinely supply patients in the ICU with invasive and painful care that will not help the patients survive even their hospitalization. This is the kind of pointless care that even the most basic protocol would triage against. Perhaps this widespread reflection on triage standards will draw our attention to our ongoing custom of supplying burdensome and inefficacious care to those near the end of life (EoL) – care that most healthcare providers would not want for themselves. This essay argues that reflecting on triage could help us improve EoL care. **Full text:** <https://bit.ly/3ii0xeb>

N.B. Additional articles on triaging the terminally ill noted in Media Watch 20 April 2020 (#662, pp.1-2).

Older persons' thoughts about death and dying and their experiences of care in end-of-life: A qualitative study

BMC NURSING | Online – 16 December 2020 – This study indicates a need for older persons to talk about death, dying and end-of-life issues. Giving older persons the opportunity to talk about what worries them and what they perceive to be meaningful and enabling them to do so could improve their quality of life

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(QoL). Even though the life expectancy is not long in older persons living in nursing homes, there is a possibility that the need for care and what is perceived as meaningful change over time. Therefore, a continuous dialogue about desires and concerns via conversations with staff is necessary to improve the final stage in life among older persons. Thus, the staff in nursing homes need to be trained and supported in talking about the sensitive subjects of dying and death. Furthermore, this study highlighted that the co-residence of cognitively healthy persons and persons with dementia in the same ward adversely affected cognitively healthy persons. This situation resulted in insufficient time to both handle the care needs of persons with dementia and have conversations that cognitive healthy persons desire. The results revealed that the needs of the cognitively healthy persons had to be deprioritized, and there was no time for them to talk about their thoughts about existence that could have given them a better QoL. The sense of community among the older persons that might have been expected at a nursing home was lost when cognitively impaired residents were not only difficult to communicate with but were even perceived as disturbing. **Full text:** <http://bit.ly/2Ke1E2e>

N.B. Additional articles on end-of-life care in nursing homes and long-term care facilities noted in Media Watch 10 August 2020 (#678, p.9), 14 September 2020 (#683, p.4), 21 September 2020 (#684, p.8), and 2 November 2020 (#690, p.10).

Hospice care self-efficacy among clinical medical staff working in the coronavirus disease 2019 (COVID-19) isolation wards of designated hospitals: A cross-sectional study

BMC PALLIATIVE CARE | Online – 10 December 2020 – A large number of patients with severe COVID-19 face death in hospital. The aim of this study was to investigate hospice care self-efficacy and identify its predictors among Chinese clinical medical staff in COVID-19 isolation wards of designated hospitals. Nurses and physicians reported a moderate level of hospice care self-efficacy during the COVID-19 pandemic. Hospice care self-efficacy was promoted by better self-competence in death work, effective coping strategies, higher level of positive aspects of caregivers, and experience of hospice care before the COVID-19 pandemic; however, it was reduced by experience of occupational exposure in fighting against the COVID-19 pandemic. Exploring the traditional Chinese philosophy of life to learn from its strengths and make up for its weaknesses and applying it to hospice care may provide a new directions for facing death or dying during the COVID-19 pandemic. Additionally, health systems could carry out continuous hospice care education to promote medical staff's self-competence in death work by improving their hospice care knowledge and skills. Taking effective measures to mobilize positive psychological resources and providing safer practice environments to avoid occupational exposure are also essential for the improvement of the hospice care self-efficacy of nurses and physicians to effectively deal with death or dying when fighting against the COVID-19 pandemic. **Full text:** <https://bit.ly/3oTEZHj>

Related:

- *FRONTIERS IN PSYCHIATRY* | Online – Accessed 17 December 2020 – ‘**Changes in communicating bad news in the context of COVID-19: Adaptations to the SPIKES protocol in the context of tele-medicine.**’ The death/dying process has profound repercussions on the mental health of patients, family members and friends submitted to it. These consequences bring fear, sadness, feeling of loneliness, abandonment and anguish. The representations of this process depend on social, economic, political and historical factors in which that community is inserted. Several studies have already demonstrated difficulties on the part of health professionals in dealing with issues related to terminality. Therefore, these professionals have difficulty in the realization of effective communication. **Full text:** <https://bit.ly/3p0dz2d>

Death rounds to support critical care nurses: A qualitative study

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 12 December 2020 – Providing end-of-life care has a significant psychological impact on critical care nurses. Little is known about whether critical care nurses find death rounds useful as a support system. The study was conducted at a 20-bed medical intensive care unit in a 1,200-bed public tertiary hospital in Singapore. Critical care nurses valued attending death rounds.

They found death rounds to be an outlet to express themselves and remember patients, to draw and give peer support, to build nursing and interprofessional cohesiveness and to learn to improve palliative care. The death rounds were optimal when they felt safe to share, when there was a good facilitator, when the hierarchy was flat and when the audience was interdisciplinary. The barriers to a successful death round were the rounds being too formal, timing and not knowing the patients. **Abstract:** <https://bit.ly/346aNA5>

“She’s dying and I can’t say we’re married?”: End-of-life care for LGBT older adults

THE GERONTOLOGIST | Online – 11 December 2020 – Lesbian, gay, bisexual, and transgender (LGBT) older adults are at particular risk for receiving inequitable end-of-life (EoL) care. Their healthcare wishes may be ignored or disregarded, their families of choice are less likely to be included in their decision-making, and they may experience increased isolation, bullying, mistreatment, or abuse, which ultimately contribute to receipt of poor-quality healthcare. This is particularly important during sensitive transitions along the care continuum to EoL settings; 43% of respondents of a 2018 survey of 865 hospice professionals reported having directly observed discriminatory behavior toward LGBT patients. Lack of visibility and accountability perpetuates vulnerabilities and the potential for discriminatory treatment. Unfortunately, while other areas of healthcare have prioritized and normalized collecting sexual orientation and gender identity (SOGI) data, hospices do not routinely assess patients’ SOGI in the context of EoL wishes and decisions. Drawing insight from a sample of 31 in-depth interviews with older LGBT adults, this article focuses on one participant’s story – Esther’s. The authors chose her story to illustrate how care can be compromised at the EoL if an open discussion with patients about what and who matters most to them at the EoL is avoided. **Abstract:** <https://bit.ly/3a140XF>

N.B. Additional articles on hospice and PC for LGBT older adults noted in Media Watch 7 December 2020 (#695, p.6).

Bolstering general practitioner palliative care: A critical review of support provided by Australian guidelines for life-limiting chronic conditions

HEALTHCARE | Online – 11 December 2020 – General practitioners (GPs) are increasingly expected to provide palliative care (PC) as ageing populations put pressure on specialist services. Some GPs, however, cite barriers to providing this care including prognostication challenges and lack of confidence. PC content within clinical practice guidelines might serve as an opportunistic source of informational support to GPs. This review analysed PC content within Australian guidelines for life-limiting conditions to determine the extent to which it might satisfy GPs’ stated information needs and support them to provide quality end-of-life care. The nine guidelines meeting inclusion criteria were heterogenous in scope and depth of PC domain coverage. The “communication” needs domain was best addressed while patient physical and emotional needs were variably covered. Spiritual, out-of-hours, terminal care and aftercare content was scant. Few guidelines addressed areas GPs are known to find

challenging or acknowledged useful decision-support tools. A template covering important domains might reduce content variability across guidelines. **Full text:** <http://bit.ly/2lR9tu5>

Extract from *Healthcare* article

Despite GP uncertainty as to what constitutes PC, when it might be introduced, and how best to communicate a transition to the end of life phase to patients, most guidelines analysed did not include this foundational information. The role of the “impeccable assessment” of patient needs advocated by the World Health Organization definition of PC was absent from all guidelines. Furthermore, most guidelines did not mention the availability of several well-established tools for identifying PC needs such as question prompts (e.g., the surprise question) or practical indicator tools such as the Supportive & Palliative Care Indicators Tool.

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Noted in Media Watch 30 November 2020 (#694, p.10):

- *JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 19 November 2020 – ‘**More proactive GPs, well timed, and less acute care: A clustered, partially controlled before-after study.**’ This study investigated three groups of possible effects of the implementation of an integrated, multidisciplinary palliative care (PC) pathway: GPs’ experiences, experiences and satisfaction of relatives of patients, and healthcare utilization (primary care, hospital care, and medication). GPs reported not only that palliative patients die more often at home (their preferred place of death), but also that they now act more proactively toward palliative patients. More proactive attitude of GPs is seen in other studies, where the proactive assessment and palliative treatment were set as priorities. **Full text:** <https://bit.ly/398Ms0g>

Noted in Media Watch 9 November 2020 (#691, p.5):

- *BMC FAMILY PRACTICE* | Online – 31 October 2020 – ‘**Home-based palliative care management: What are the useful resources for general practitioners? A qualitative study among GPs in France.**’ The problems related to the home-based practice of palliative care (PC) by GPs are well known, yet few studies highlight the resources actually used by GPs. This study outlines such resources, including structures (regional assistance networks, hospitalization at home), the use of resource personnel (medical, paramedical and family), and schedule organization. A GP’s status implies a tacit moral contract that involves managing home-based PC when needed. This moral responsibility is more a resource than a burden for GPs who rely on their care values in order to face difficulties. **Full text:** <https://bit.ly/2HW6T5f>

Noted in Media Watch 26 October 2020 (#689, p.8):

- *EUROPEAN JOURNAL OF GENERAL PRACTICE* | Online – 20 October 2020 – ‘**Implementation of primary palliative care in five Belgian regions: A qualitative study on early identification of palliative care needs by general practitioners.**’ GPs expressed a desire for therapeutic freedom. Family practitioners were worried that imposing guidelines and standardisation of palliative care (PC) according to theoretical ideals would reduce the creativity of “tailor-made care.” More than in PC protocols, GPs are interested in feedback and peer review methods to improve their own PC skills. The phrase “palliative care” is still used with difficulty in all five regions. Some GPs never use these words while others have a personal mission to diminish the PC taboo. **Full text:** <https://bit.ly/35iLMSG>

“Why couldn’t I go in to see him?” Bereaved families’ perceptions of end-of-life communication during COVID-19

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 15 December 2020 – The COVID-19 pandemic has resulted in rapid changes to end-of-life (EoL) care for hospitalized older adults and their families, including visitation restrictions. The authors examined bereaved families’ perceptions of the quality of EoL communication among Veterans, families and staff in Veterans Affairs (VA) medical centers [across the U.S.] during the COVID-19 pandemic. Bereaved family members identified contextual factors perceived to impact communication quality including: allowing family at the bedside when death is imminent, fears that the patient died alone, and overall perceptions of VA care. Characteristics of perceived high-quality communication included staff availability for remote communication and being kept informed of the patient’s condition and plan of care. Low-quality communication with staff was perceived to result from limited access to staff, insufficient updates regarding the patient’s condition, and when the family member was not consulted about care decision-making. Communication quality with the patient was facilitated or impeded by the availability and use of video-enabled remote technologies. Communication between patients, families, and healthcare teams at the EoL remains critically important during times of limited in-person visitation. Families report that low-quality communication causes profound distress that can affect the quality of dying and bereavement. Innovative strategies are needed to ensure that high-quality communication occurs despite pandemic-related visitation restrictions. **Abstract:** <https://bit.ly/3r26boX>



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Delivery of palliative care in acute care hospitals: A population-based retrospective cohort study describing the level of involvement and timing of inpatient palliative care in the last year of life

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 December 2020 – Much end-of-life (EoL) care is provided in hospital, yet little is known about the delivery of palliative care (PC) during EoL hospitalizations. The authors undertook a population-based retrospective cohort study of adults in Ontario, Canada, who died between 1 April 2012, and 31 March 2017, and had at least one acute care hospitalization in their last year of life. They developed a hierarchy of inpatient PC involvement reflecting the degree to which care was delivered with palliative intent. This hierarchy was based on PC diagnosis and service provider codes on hospitalization records and physician claims. The authors examined variations in the level of PC involvement across key patient characteristics. In the last year of life, 65.1% of hospitalizations had no indication of PC involvement, 16.7% had a low level of involvement, 13.5% had a medium level of involvement, and 4.7% had a high level of involvement. Most hospitalizations with PC involvement (85.6%) occurred in the two months before death. Compared to patients who received no inpatient PC, patients who received a high level of PC involvement tended to be younger, died of cancer, resided in urban or lower income neighborhoods, and had fewer chronic conditions. **Abstract:** <https://bit.ly/2LSxrpV>

Pediatric Project ECHO®

A virtual community of practice to improve palliative care knowledge and self-efficacy among interprofessional healthcare providers

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 December 2020 – Healthcare providers (HCPs) require ongoing training and mentorship to fully appreciate the palliative care (PC) needs of children. Project ECHO® (Extension for Community Healthcare Outcomes) is a model for delivering technology-enabled interprofessional education and cultivating a community of practice among HCPs who care for children with life-limiting illness. Project ECHO has demonstrated feasibility and acceptability among community HCPs across Canada and was successful in achieving perceived changes in knowledge and self-efficacy. Although several performance-related outcomes were evaluated at six months, additional research is needed to determine the long-term impacts of ECHO. Future studies will report on self-assessed knowledge, self-efficacy, and practice impact after 12 months of participation in the program. The ECHO model is conducive for the delivery of continuing professional education to geographically dispersed HCPs providing pediatric PC. This program may assist other institutions in developing training programs to enhance community-based pediatric PC. **Full text:** <https://bit.ly/2WqK3qI>



The Heart of Living & Dying: Upstreaming advance care planning into community conversations in the public domain in Northern Ireland

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 11 December 2020 – This article provides an evaluation of the Heart of Living & Dying (HLD) Initiative. This initiative is a group process that attempts to bring advance care planning (ACP) into the public domain. It encourages participants to consider what matters to them in their living along with their hopes, preferences, and wishes for their final years and end-of-life care. An inductive, interpretive, and naturalistic approach allowed the researcher to study these phenomena in their natural setting i.e., the community. All participants in the HLD speak from a personal perspective irrespective of any professional background. It transpired that 16 respondents worked in health and social care, which subsequently became noteworthy in the findings. Three key themes were identified: 1) Feeling emotionally safe enough to have such sensitive conversations is vital; 2) Participating in the HLD process increases the confidence of those participants who worked in health and social care, to undertake ACP conversations; and, 3) Planning ahead is a complex, staged process rather than a single record-making event. The COVID-19 pandemic crisis reinforced the need to upstream ACP initiatives such as the HLD, as the norm for everyone, since all of us will one day die. **Full text:** <https://bit.ly/37eiOpe>

Memorialisation during COVID-19: Implications for the bereaved, service providers and policy-makers

PALLIATIVE CARE & SOCIAL PRACTICE | Online – 15 December 2020 – If, as seems likely, modes of working and learning that blend the public and the private are likely to persist in a post-pandemic world, so too can we expect to see lasting changes to memorialisation and bereavement support. We will need to revive and renew public forms of memorialisation, draw upon the best strategies that have been generated during the pandemic, and seek the advice of those bereaved during the pandemic to ensure that their experiences inform their communities and end-of-life services in particular in integrating the old and the new. These conversations need to start now so that all participants can focus not only on the problems created by COVID-19 but also the possibilities for building a more compassionate society in the future. **Full text:** <http://bit.ly/38dkG0H>

Estimating the current and future prevalence of life-limiting conditions in children in England

PALLIATIVE MEDICINE | Online – 15 December 2020 – The prevalence of children with a life-limiting or life-threatening condition in England is predicted to continue to rise. The prevalence is higher in ethnic minority groups which may in part explain this rise. Data on 4,543,386 hospital episodes for 359,634 individuals were included in this study. The prevalence of children with a life-limiting condition rose from 26.7 per 10,000 in 2001-2002 to 66.4 per 10,000 in 2017-2018. Using a more restricted definition of a life-limiting condition reduced the prevalence from 66.4 to 61.1 per 10,000 in 2017-2018. Highest prevalence was in the under one-year age group at 226.5 per 10,000 and children with a congenital abnormality had the highest prevalence (27.2 per 10,000). These data are important for healthcare planners and policymakers as children and young people will require healthcare services which may include pediatric palliative care (PC). The prevalence is by far the greatest in children under one year of age, and this group should be seen as a priority for receiving PC as mortality rate is also highest in the under one year age-group. Further research needs to identify the needs and complexity of these children which goes beyond their underlying diagnoses. This can only be resolved by recording of complexity and needs rather than diagnoses alone. **Full text:** <http://bit.ly/3mqrVY0>

Related:

- *PALLIATIVE MEDICINE* | Online – 18 December 2020 – ‘**A meta-ethnographic study of fathers’ experiences of caring for a child with a life-limiting illness.**’ To the authors’ knowledge, this is the first meta-ethnography focusing on fathers’ experiences of caring for their children with life-limiting conditions and the first attempt to develop a conceptual model. Although fathers’ characteristics and settings varied greatly, this meta-ethnography conceptualised their experiences during their personal and family crises, generated by their children’s life-limiting conditions. It provides a dramatic window into the salience of these experiences in various stages of children’s illness and treatment. A limitation is the reliance on data presented in included studies, which may not fully reflect the original data. **Full text:** <http://bit.ly/37vqlA3>

Home or hospital as the place of end-of-life care and death: A grounded theory study of parents’ decision-making

PALLIATIVE MEDICINE | Online – 14 December 2020 – Despite the fact that home is often advocated as the preferred place of death and as a “marker” of a “good death” for children, this is not supported by robust evidence. Research on location of end-of-life care (EoLC) and death has been more outcome-focused, documenting parents’ and clinicians’ preferences or epidemiological trends with regard to the achieved place of death. Studies focus on “what” decisions parents make at the end of the child’s life, rather than “how” these decisions are reached. The authors of this study identify six salient factors affecting decision-making about place of care and place of death: 1) Awareness of dying; 2) Perceived professionals’ competence; 3) Parents’ perceived competence to deliver care at home; 4) Parents’ view of



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symptom management; 5) Timing of decision-making; and, 6) Being a “good parent.” The authors identify four distinct processes through which decisions are made: 1) Mutual consensus; 2) Accommodation; 3) Acceding to professional decisions; and, 4) Imposing decisions by excluding professionals. Parents should be helped to make decisions about place of EoLC and place of death in such a way that they are not only truly informed by caring professionals but also presented timely with options so as to develop competence to deliver care at home, should they choose to do so. Perceptions of what “good parenting” entails, should be explored in deliberations with parents as decisions are reached. Policymakers should improve EoLC at all sites since home and hospital are desirable to different families, for different reasons, at different times. **Full text:** <https://bit.ly/3qXERrM>

N.B. Society for the Care of Children and Families Facing Illness and Death (Athens, Greece) website: <https://bit.ly/3a4vQYa>

Noted in Media Watch 26 October 2020 (#689, p.6)

- *BMC PALLIATIVE CARE* | Online – 24 October 2020 – ‘**Family experiences with palliative care for children at home: A systematic literature review.**’ The results of this review underpin the lack of research on sick children and their siblings’ perspectives on palliative care (PC) at home. Children should be given an opportunity to express and communicate their experiences, feelings and needs themselves, and not only through their parents. Their experience is important for optimising the quality of care at end of life and identifying the needs of these vulnerable children is crucial. There is a gap in the knowledge about children’s needs that further research should address. Few countries are represented in the literature on families’ experiences with PC for children at home... **Full text:** <https://bit.ly/3mj0Q9H>

Noted in Media Watch 28 September 2020 (#685, p.11):

- *JOURNAL OF PEDIATRIC NURSING*, 2020;55(6):126-133. ‘**Home-based end-of-life care for children and their families: A systematic scoping review and narrative synthesis.**’ This review aimed to establish the international evidence base relating to children’s end-of-life care (EoLC) at home. Engagement of families in EoLC planning discussions was identified as a key factor to facilitate choice of setting. Consistent themes suggest providing access to care in the home 24/7 by a team of professionals with specialist pediatric palliative care knowledge is an essential aspect of any model of home-based EoLC. This is the first comprehensive review of home-based EoLC for children which offers a valuable contribution to policy, practice and research. **Abstract (w. list of references):** <https://bit.ly/2HhoFQ2>

N.B. Additional articles on home-based pediatric PC noted in this issue of Media Watch. See also #684 of the weekly report (pp.10-11).

How to measure the effects and potential adverse events of palliative sedation? An integrative review

PALLIATIVE MEDICINE | Online – 14 December 2020 – The European Association for Palliative Care considers sedation to be an important and necessary therapy in the care of selected palliative care patients with otherwise refractory distress. Prudent application of this approach requires due caution and good clinical practice. Inattention to potential risks and problematic practices can lead to harmful and unethical practice which may undermine the credibility and reputation of responsible clinicians and institutions as well as the discipline of palliative medicine more generally. Procedural guidelines are helpful to educate medical providers, set standards for best practice, promote optimal care and convey the important message to staff, patients and families that palliative sedation is an accepted, ethical practice when used in appropriate situations. The association aims to facilitate the development of such guidelines by presenting a 10-point framework that is based on the pre-existing guidelines and literature and extensive peer review.¹ **Full text:** <https://bit.ly/3gJL9qm>



1. ‘European Association for Palliative Care recommended framework for the use of sedation in palliative care,’ *Palliative Medicine*, 2009;23(7):581-593. **Abstract:** <http://bit.ly/2E7KeOV>

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Noted in 28 September 2020 (#685, p.6):

- *BMC PALLIATIVE CARE* | Online – 23 September 2020 – ‘**What do you mean by “palliative sedation”?**’ There is a lack of consensus and a high potential even for different kinds of confusion regarding the labeling of sedation practices in palliative care (PC). Calling for uniformity of definitions alone, without an understanding of the underlying types of problems, will not help to improve the conceptual situation concerning sedation in PC. Instead, the categories presented and the authors’ analyses of impact on conceptual problems in different ways can serve as a starting point when constructing terminology. The authors’ distinction of different purposes of the definition and implications may further the dissent on pre-emption of the ethical dispute about sedation practices in PC. **Full text:** <https://bit.ly/2FVyfaW>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 19 September 2020 – ‘**Clinical aspects of palliative sedation in prospective studies. A systematic review.**’ Clinical guidelines have been developed, but they are mainly based on expert opinion or retrospective chart reviews. Therefore, evidence for the clinical aspects of palliative sedation is needed. Ten prospective articles were included... Most frequently reported refractory symptoms were delirium (41-83%), pain (25-65%), and dyspnoea (16-59%). In some articles, psychological and existential distress were mentioned (16-59%). A few articles specified the tools used to assess symptoms. Future research needs to evaluate the effectiveness of palliative sedation for refractory symptom relief. **Abstract (w. list of references):** <https://bit.ly/33QyJCC>

N.B. Additional articles on palliative (or terminal) sedation noted in Media Watch 20 July 2020 (#675, p.7).

Student-reported attitudes during an interprofessional palliative care learning experience: Implications for dual-professional identity, interdisciplinary bias, and patient outcomes

PALLIATIVE MEDICINE REPORTS | Online – 11 December 2020 – This study identified the existence of interprofessional biases and prejudices that may impede collaboration among healthcare professionals resulting in reduced healthcare outcomes. Faculty and health educators are encouraged to embed interprofessional education (IPE) into a multidisciplinary curriculum that dismantles preexisting interdisciplinary biases and stereotypes, and constructs dual-professional identity. Palliative care (PC) could possibly serve as the perfect milieu to implement IPE in multiple healthcare disciplines, especially given that the competencies of PC align with IPE/ Interprofessional Collaborative Practice competencies. PC requires a cohesive interprofessional team with effective communication skills, exemplary ethical standards, and a commitment to patient- and family-centered care. This approach requires well-implemented interventions, with holistic services that integrate the physical, social, spiritual, and environmental needs of the patient and family. Interprofessional holistic care distinguishes palliative services from traditional, siloed healthcare services. The authors’ recommendations for future IPE activities include: 1) Explore ways that educators can help students become aware of their existing interprofessional biases; 2) Model and train students to act in a supportive manner toward other healthcare disciplines; 3) Create IPE opportunities to apply collaborative practice skills (communication, teamwork, ethics, and roles/responsibilities) in simulation and clinical settings; and, 4) Design more inclusive IPE PC activities to explore the role of other constituencies such as family members, social work, and physical therapy. **Full text:** <https://bit.ly/37gLrID>

Valuing life and evaluating suffering in infants with life-limiting illness

THEORETICAL MEDICINE & BIOETHICS | Online – 17 December 2020 – The authors explore three separate questions that are relevant to assessing the prudential value of life in infants with severe life-limiting illness. First, what is the value or disvalue of a short life? Is it in the interests of a child to save her life if she will nevertheless die in infancy or very early childhood? Second, how does profound cognitive impairment affect the balance of positives and negatives in a child’s future life? Third, if the life of a child with life-limiting illness is prolonged, how much suffering will she experience and can any of it be alleviated? Is there a risk that negative experiences for such a child (suffering) will remain despite the provision of palliative care? The authors argue that both the subjective and objective components of well-being for children could be greatly reduced if they are anticipated to have a short life that is affected by profound cognitive impairment. This does not mean that their overall well-being will be negative, but rather that there may be a higher risk

Cont.

of negative overall well-being if they are expected to experience pain, discomfort, or distress. Furthermore, the authors point to some of the practical limitations of therapies aimed at relieving suffering, such that there is a risk that suffering will go partially or completely unrelieved. Taken together, these considerations imply that some life-prolonging treatments are not in the best interests of infants with severe life-limiting illness. **Full text:** <https://bit.ly/3p3b67h>

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Prison Hospice: Backgrounder – Updated 12.15.2020 –

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 at the Palliative Care Network website: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk. Philadelphia, PA



Would this backgrounder
be of interest to a colleague?

Articles added since the 09.15.2020 update of the backgrounder:

New England Journal of Medicine: 'Flattening the curve for incarcerated populations: COVID-19 in jails and prisons' (p.2)

Victims & Offenders: 'The impact of COVID-19 outbreaks in prisons, jails, and community corrections systems throughout Europe' (p.2)

Health & Justice: 'Identifying barriers and facilitators to implementing advance care planning in prisons...' (p.15)

Canadian Family Physician: 'Life and death in Canada penitentiaries' (p.15)

The Irish Examiner: 'Watchdog criticises refusal to allow prisoner to die in a hospice' (p.18)

Inside Time: 'Prisons "dying from poor care"' (p.21)

Palliative Medicine: 'Caring, sharing and declaring: How do hospices support prisons to provide palliative and end-of-life care?' (p.22)



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>

Publishing Matters

Changes in medical scientific publication associated with the COVID-19 pandemic

MEDICAL JOURNAL OF AUSTRALIA, 2020;213(11):496-499. The COVID-19 pandemic has resulted in wide-ranging health, social and economic impacts. By October 2020, global cases exceeded 41 million, with 1.1 million deaths. Urgent requirements for information were met with data on epidemiology, clinical features and recommended management being circulated on social media and pre-publication servers. While this has allowed timely sharing of data, it has also brought risk of misinformation, with consequent changes to medical practice and misdirection of scarce resources based on flawed evidence. Medical publishing uses peer review to provide independent and critical assessment to verify data integrity, validity of interpretations, and confidence in conclusions. This process can take many weeks; however, in a rapidly spreading pandemic, speed is a competing priority. The authors hypothesised that these considerations may have altered the nature of medical publication. Accordingly, they characterised various aspects of COVID-19-related articles published in the five leading general medical journals with the highest impact factors [i.e., *Annals of Internal Medicine*, *British Medical Journal*, *Journal of the American Medical Association*, *The Lancet*, *The New England Journal of Medicine*] we compared with an equivalent period in the preceding year. **Full text:** <https://bit.ly/2LDgoYZ>

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

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
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/36XAaXg>

[Scroll down to 'Media Watch']

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']

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/3EPKUAC>

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

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

South America

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

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