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

COVID-19: End-of-Life Care

‘Integrating palliative care into COVID-19 planning’ (p.11), in Insight.


‘What should palliative care’s response be to the COVID-19 epidemic?’ (p.11), in Journal of Pain & Symptom Management.

‘Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy’ (p.10), in MEDRxIV.

U.S.A.

Hospitals need to prepare for life and death decisions during the Coronavirus pandemic

MASSACHUSETTS | The Boston Globe – 26 March 2020 – As the new Coronavirus pandemic spreads across the U.S., we must learn from those countries that are already feeling the brunt of the crisis. Reports from Italy describe doctors making decisions on the fly regarding whom to prioritize for medical resources as waves of very sick patients turn to hospitals for care during the COVID-19 crisis. These stories highlight the urgent need for the U.S. to come together as communities and within healthcare institutions to craft clear, equitable, and transparent policies for rationing healthcare services. We must prioritize making these decisions before the crisis begins to overwhelm our healthcare system. Modeling conducted at the Harvard T.H. Chan School of Public Health indicates excess demand for ICU beds throughout the country will outstrip capacity by as much as 600% if the current trajectory stays in place. And, even in a best-case scenario of “flattening the curve” of new infections, excess demand will likely remain at 200%. https://bit.ly/3brZlk7

Shortage of palliative care in the U.S. could amplify suffering for Coronavirus patients

USA TODAY | Online – 25 March 2020 – Some experts worry that a long-standing shortage of palliative care (PC) professionals – who focus on the physical pain and mental and spiritual distress caused by serious illness – could leave many COVID-19 patients in distress. “There is already a shortage, which will

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only worsen as demand goes up because of current events,” said Dr. Arif Kamal, a PC researcher at the Duke University School of Medicine. The supply of PC teams could be further diminished if many healthcare providers become ill themselves. PC staffing could not meet the country’s needs even before the Coronavirus appeared. Among all U.S. hospitals with at least 50 beds, 72% provide PC, according to a report from the Center to Advance Palliative Care. That number is dramatically lower in certain states. Fewer than 40% of hospitals provide PC in Alabama, Mississippi, New Mexico, Oklahoma and Wyoming. https://bit.ly/33Mrm3f


Related:

- MASSACHUSETTS | The New Yorker – 21 March 2020 – “Inside a new effort to create guidelines for treating COVID-19 patients.” A team at Brigham & Women’s Hospital, which is affiliated with Harvard Medical School, has released guidelines for treating patients who become critically ill with COVID-19. The document is a work in progress, which will be updated as its creators receive feedback from other physicians and gather more information about the course of the disease. As they are today, the guidelines offer medical professionals advice for a multitude of possible scenarios... Two final sections, “The Role of Palliative Care” and “Ethical Considerations & Resource Allocation,” remain blank, with the note, “This section is in progress.” https://bit.ly/2U9L99n


Hospitals consider universal do-not-resuscitate orders for Coronavirus patients

THE WASHINGTON POST | Online – 25 March 2020 – Hospitals on the front lines of the pandemic are engaged in a heated private debate over a calculation few have encountered in their lifetimes – how to weigh the “save at all costs” approach to resuscitating a dying patient against the real danger of exposing doctors and nurses to the contagion of Coronavirus. The conversations are driven by the realization that the risk to staff amid dwindling stores of protective equipment … may be too great to justify the conventional response when a patient “codes,” and their heart or breathing stops. Several large hospital systems … are looking at guidelines that would allow doctors to override the wishes of the patient or family members on a case-by-case basis due to the risk to doctors and nurses, or a shortage of protective equipment, say ethicists and doctors involved in those conversations. But they would stop short of imposing a do-not-resuscitate order on every Coronavirus patient. https://wapo.st/2JfPhhV

Senate bill would allow telehealth for hospice face-to-face encounters, pause sequestration

HOSPICE NEWS | Online – 22 March 2020 – Provisions of a massive stimulus package currently being debated in the U.S. Senate would allow hospices to use telehealth in lieu of face-to-face encounters as well as temporarily ending the practice of sequestering 2% of hospice payments from the U.S. Centers for Medicare & Medicaid Services (CMS). The Coronavirus Aid, Relief & Economic Security Act, also called the CARES ACT, is designed to stimulate the economy and provide aid to businesses and individuals reeling from the impact of the COVID-Pandemic. CMS Conditions of Participation currently require hospice physicians to conduct a face-to-face visit in order to certify or recertify patients for hospice care. Earlier in the crisis, CMS took steps to temporarily expand the use of telehealth, but hospice face-to-face encounters were not included. https://bit.ly/33CYsCq
Aged care, end-of-life and palliative care: Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee report

AUSTRALIA (Queensland) | Queensland Parliament – 24 March 2020 – In November 2018, the Legislative Assembly ordered the committee to undertake a major inquiry into the delivery of aged care, end-of-life care and palliative care, and community and health practitioners’ views on voluntary assisted dying. This report presents the committee’s findings and recommendations. The committee resolved to report findings on voluntary assisted dying separately. The current Coronavirus pandemic highlights the importance of ensuring the aged care sector is properly funded, resourced and regulated to enable the appropriate level of care to be provided. This should be regardless of whether an elderly person is a resident of an aged care facility or resides in their own home. The committee holds grave concerns for the welfare of older Australians trying to access care at home or in residential aged care facilities. Many older Australians die while waiting for their home care packages. Download/view at: https://bit.ly/33LGo9c

Noted in Media Watch 10 June 2019 (#617, p.3):

- AUSTRALIA (Queensland) | The Weekly Source (Balmain East, New South Wales) – 4 June 2019 – ‘Public submissions to Queensland inquiry into aged care, palliative care and voluntary assisted dying seem focus on end-of-life decisions.’ The inquiry was initially announced by the Queensland Parliamentary Health, Communities, Disability Services and Domestic and Family Violence Committee in November 2018 … and received more than 5,000 submissions before the deadline in April. While the submission scope included aged care, an initial glance at the first 500 suggests Queenslanders are mostly concerned with end-of-life and palliative care issues rather than home or residential aged care. http://bit.ly/2WadhqJ

Specialist Publications

End-of-life care preferences of the general public and recommendations of healthcare providers: A nationwide survey in Japan

BMC PALLIATIVE CARE | Online – 24 March 2020 – The first important finding was that the general public preferred more aggressive treatment and life-sustaining treatment (LST) than that recommended by healthcare providers, although CPR was less preferred compared with care staff recommendations. On the other hand, healthcare providers recommended limited medical care, i.e., life-prolonging care that promotes comfort and can be withdrawn, more often than was wanted by the general public. Previous studies demonstrate the general public has poor knowledge regarding the benefits of aggressive treatment and LST, such as CPR, parenteral nutrition, and hydration, for terminally ill cancer patients. Therefore, the general public might overestimate the success rate of CPR and benefits of parenteral nutrition and hydration in late-stage cancer patients. The second important finding was the work-place, participation in a nationwide education program on end-of-life (EoL) discussion, and experience in EoL care were factors significantly influenced the recommendations of healthcare providers about EoL care and LST. Full text: https://bit.ly/3akFbr

Publishing Matters

‘Thousands of Australian academics on the editorial boards of journals run by predatory publishers’ (p.15), in Learned Publishing.
Impact of socio-economic status on end-of-life costs: A systematic review and meta-analysis

BMC PALLIATIVE CARE | Online – 23 March 2020 – The aim of this review was to evaluate the relationship between socio-economic status (SES) and health expenditure at end of life (EoL). The authors found that patient SES was significantly correlated with EoL expenditures. The evidence suggested significant heterogeneity in units of cost, length of EoL period, extent of adjustment, and directionality of conclusions. One of the key factors that accounted for the variation in SES-EoL cost inequalities was adjustment for comorbidities. When unadjusted for comorbidities, low SES was associated with lower total and hospital EoL expenditure. Conversely, when adjusted for comorbidities, low SES was associated with higher total and hospital EoL expenditure. Irrespective of adjustment, low SES patients had lower specialist, out-of-pocket, and drug expenditure at EoL even within jurisdictions providing universal health coverage to its citizens. To the best of the authors’ knowledge, their systematic review and meta-analyses were the first to examine the effects of socio-economic variation on EoL cost of care. Full text: https://bit.ly/3docah7

Noted in Media Watch 29 April 2019 (#612, p.11):

- PLOS MEDICINE | Online – 23 April 2019 – ‘Socio-economic position and use of healthcare in the last year of life: A systematic review and meta-analysis.’ This study found consistent evidence from high-income countries that low socio-economic position (SEP) is a risk factor across several components of service use at the end of life (EoL), including dying in hospital rather than at home, receiving acute hospital-based care in the last 3 months of life, and not receiving specialist palliative care (SPC) in the last year of life. The authors also found evidence of a pervasive social gradient in place of death and use of SPC. These findings should stimulate widespread efforts to reduce socio-economic inequality towards the EoL. Full text: http://bit.ly/2GsS4ma

Systematic review of qualitative studies on participants in the decision-making process about the location of care of the elderly

BMJ OPEN | Online – 23 March 2020 – The main result of this review has been the high variability found in the literature on how the decision on the location of elderly care is taken. There is no pattern or single way to proceed, and on some occasions, the way the people involved act or perceive the situation varies due to the influence of some of the other groups of participants studied. Despite that, this review has obtained relevant and really noteworthy results as far as the roles and degrees of involvement are concerned, thanks to having focused on the main participants in this process, those who are directly affected by the decision: the elders. The different ways in which the elderly is involved in the decision-making process have been analysed, to a greater or lesser extent, as well as how those closest to them, their family members, relate to the elders when it comes to making this decision. In this regard, it is highly interesting how some behaviours that may seem positive a priori, such as taking into account the elder, are not always linked to positive behaviours from the family members. However, the existence of other participants in the literature also bears mentioning, who have been classified into two groups: healthcare and social services professionals (physician being the most often mentioned category, followed by social worker and nurse), and other relevant participants in the decision-making process (the elder’s friends and neighbours being the most often mentioned). Full text: https://bit.ly/2vJSNy7

Preferred place of death in paediatric, teenage and young adult haematology-oncology patients: A retrospective review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 24 March 2020 – Clinical/demographic details, including preferred and actual places of death, were recorded for 121 patients who died between 2012 and 2016 at a tertiary haematology-oncology centre. 74 (61%) patients had a documented discussion regarding place of death preference. Where a preferred location was identified, 72% achieved it. All patients who wanted to die in the hospital or a hospice did, but only 58% of patients who wanted to die at home achieved this. Of the 42% who wanted to die at home but did not, 59% of these were due to rapid deterioration in clinical status shortly after the discussion. Having supportive treatment in the last month of life was associated with increased odds of achieving the preferred place of death versus those who were undergoing chemotherapy/radiotherapy. Clinicians should be encouraged to address end-of-life (EoL) preferences at an early stage, with information provided adequately. Full text: https://bit.ly/39dukPi
Early specialised palliative care: interventions, symptoms, problems

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 27 March 2020 – This is one of the first studies to meticulously investigate the content of interventions documented in the medical records for patients receiving early specialist palliative care (SPC). The objective was to characterise the content of interventions delivered in early SPC in the Danish Palliative Care Trial (DanPaCT), a multicentre trial with six participating sites. 145 patients were randomised to the SPC teams. According to the medical records, patients received a median of 3.5 new interventions in the 8-week intervention-period from the palliative teams. For 24 of the patients there was no documented interventions in the medical records. The most frequent symptom/problems treated were pain … and impaired physical function… The most frequent type of intervention was pharmacological… Diverse symptoms were treated with many different interventions. However, a relatively low number of interventions were documented. This may explain the lack of effect in DanPaCT but also questions whether all interventions were adequately documented. Abstract: https://bit.ly/2QRpAs9

Confidence and skills for cystic fibrosis end-of-life care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 26 March 2020 – Optimal cystic fibrosis (CF) end-of-life care (EoLC) is a challenge. There is little formal guidance about who should deliver this and how CF multi-disciplinary teams should interact with specialist palliative care (PC). The authors assessed the knowledge, experience and preparedness of both CF and PC professionals for CF EoLC. Thirty-five of a possible 63 members responded to a questionnaire – 19 CF team; 16 PC. Levels of preparedness were low in both groups. Only 11% of CF and 19% of PC team members felt fully prepared for EoLC in adult CF. 58% of CF members had no (21%) or minimal (37%) general PC training. Similarly, 69% of the PC team had no CF-specific training. All respondents desired additional education. CF team members preferred further education in general EoLC while PC team members emphasised a need for more CF-specific knowledge. Abstract: https://bit.ly/2UF9Klx

Noted in Media Watch 10 February 2020 (#652, p.9):

- JOURNAL OF PALLIATIVE MEDICINE | Online – 5 February 2020 – ‘Palliative care needs of individuals with cystic fibrosis: Perspectives of multiple stakeholders.’ Seventy adults with cystic fibrosis (CF), 100 caregivers, and 350 care team members completed surveys. While care team members reported they introduce palliative care (PC) to patients a majority of the time, adults with CF and caregivers rarely recalled learning about it. Few reported having seen a PC specialist. A majority of participants reported PC is valuable in CF care. Over 80% of participants felt PC is different in CF, most often citing the unpredictable disease course. Barriers to PC include perception that it is for dying people and lack of CF care team knowledge and training in PC. Abstract: http://bit.ly/2Uq6BaW

Noted in Media Watch 30 December 2019 (#646, p.9):

- JOURNAL OF CYSTIC FIBROSIS | Online – 17 December 2019 – ‘Prevalence of unmet palliative care needs in adults with cystic fibrosis.’ Physical and emotional burdens impair quality of life in many adults with cystic fibrosis (CF). Palliative care (PC) improves QoL in other serious illnesses, yet the full array of palliative needs amenable to PC are unknown in CF. Unmet physical and psychological palliative needs are prevalent in adults with CF. Symptoms are a stronger predictor of needs than physiologic measures. Routine screening of unmet PC needs using tools such as the Supportive Care Needs Survey-34 may enable CF care teams to optimize the provision of primary and specialist PC. Abstract: http://bit.ly/2sUrQpg

N.B. Additional articles on the PC needs of people living with CF noted in 9 September 2019 issue of Media Watch (#630, p.8).
Specialist palliative medicine physicians and nurses accuracy at predicting imminent death (within 72 hours): A short report

**BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 22 March 2020 – This study found that in the last 72 hours of life, clinicians’ predictions were accurate on between 65% and 73% of occasions, indicating that they were incorrect in their predictions on up to one in three occasions. Nurses were slightly better than doctors at distinguishing between patients who were imminently dying and those who were not, a finding maintained after comparing only the cases that had a prediction from both professions… Previous reviews have identified limited evidence about the reliability of predictions of imminent death. The results of this study are in keeping with some findings from previous studies, where it has been suggested that nursing staff are more accurate, although this is not a consistent trend. These findings warrant further research. If there is a difference between professionals then there may be something to learn from the differences between how nurses and doctors prognosticate, both locally and internationally. This is one of only a limited number of prospective studies investigating the accuracy of predicting imminent death. [Full text](https://bit.ly/39j8ZEl)

Noted in Media Watch 20 May 2019 (#614, p.8):

- **BMJ SUPPORTIVE & PALLIATIVE CARE** | Online – 10 May 2019 – ‘Imminent death: Clinician certainty and accuracy of prognostic predictions.’ The results of this study show that even when patients are very confident that a patient will die within the next 72 hours, these estimates are only correct on 75% of occasions... It is therefore important for clinicians to convey this level of uncertainty in their communications with patients and relatives and not to forget that even their most confident predictions are inaccurate 25% of the time. This suggests that while clinical predictions will continue to have a role for routine prognostication, other approaches (such as the use of prognostic scores) may be required for those cases where doctors’ estimates are indeterminate. [Full text](http://bit.ly/2Hevs9p)

Noted in Media Watch 3 December 2018 (#592, p.9):

- **BMJ OPEN** | Online – 25 November 2018 – ‘How do palliative care doctors recognise imminently dying patients? A judgement analysis.’ The methodology adopted in this study enabled a direct comparison between the accuracy of different doctors’ estimates of imminent death; this has not been done before. The approach that was taken in this study to quantify and objectively measure the ability of the “expert” group was significantly more thorough than anything which has been done before and is preferable to simply assuming that years of experience or seniority are synonymous with expertise. Judgement analysis offers a methodology to unpick clinical decision-making, clinical intuition or “gut instinct,” regarding how doctors recognise which patients are dying. [Full text](http://bit.ly/2RR5XmC)

How thinking hurts: Rumination, worry, and avoidance processes in adjustment to bereavement

**CLINICAL PSYCHOLOGY & PSYCHOTHERAPY** | Online – 26 February 2020 – This study confirms the importance of both rumination and worry in coming to terms with bereavement and suggests that both processes may hamper the recovery because they are linked with specific avoidance processes. These findings are in line with prior research on the effects and working mechanisms of rumination yet also uniquely demonstrate the role and potential function of worry in the grieving process. Future research should aim to replicate and extend these findings with more advanced designs and methodology, with the ultimate goal to improve clinical practice for severely distressed bereaved people who engage in (chronic) repetitive thought. [Full text](https://bit.ly/2UbqJt)

Noted in Media Watch 2 October 2017 (#532, p.10):

- **BEREAVEMENT CARE, 2017;36(2):58-64.** ‘Rumination following bereavement: An overview.’ The authors summarise a growing literature on rumination and mental health outcomes of bereavement and compare two main theories explaining the maladaptive effects of rumination after loss, which hold conflicting implications for clinical practice. The Response Styles Theory states that rumination is a maladaptive confrontation strategy that perpetuates distress by increasing negative cognitions, impairing problem solving and instrumental behaviour and reducing social support. Conversely, the Rumination as Avoidance Hypothesis holds that rumination may serve to avoid painful aspects of the loss, thereby hampering adjustment to bereavement. [Full text](https://bit.ly/2UpT1Wp)
Exploring community-dwelling older adults’ considerations about values and preferences for future end-of-life care: A study from Sweden

*THE GERONTOLOGIST* | Online – 21 March 2020 – There is a substantial body of research on advance care planning (ACP), often originating from English-speaking countries and focused on healthcare settings. However, studies of content of ACP conversations in community settings remain scarce. In this participatory action research project, planned and conducted in collaboration with national community-based organizations, the authors interviewed 65 older adults without known end-of-life (EoL) care needs, about their values and preferences for future EoL care. Conversations were stimulated by sorting and ranking statements in a Swedish version of GoWish cards, called the DöBra cards, and verbatim transcripts were analyzed inductively. While participants shared some common preferences about EoL care, there was great variation among individuals in how they reasoned. Although EoL preferences and prioritizations could be identical, different individuals explained these choices very differently. The authors exemplify this variation using data from four participants who discussed their respective EoL preferences by focusing on either physical, social, existential, or practical implications. A previously undocumented benefit of the GoWish/DöBra cards is how the flexibility of the card statements support substantial discussion of an individual’s EoL preferences and underlying values. Such in-depth descriptions of participants’ reasoning and considerations are important for understanding the very individual nature of prioritizing EoL preferences. The authors suggest future users of the GoWish/DöBra cards consider the underlying reasoning of individuals’ prioritizations to strengthen person-centeredness in EoL conversations and care provision. Full text: [https://bit.ly/2WFMJlm](https://bit.ly/2WFMJlm)

Palliative care and heart failure: Some remarks about cost-effectiveness and clinical results

*GIORNALE ITALIANO DI CARDIOLOGIA*, 2020;21(4):303-305. Early palliative care (PC) clearly demonstrated its efficacy in patients with heart failure, reducing symptom burden, mainly pain and depression, improving quality of life, and reducing the access to the healthcare system. However, there are not conclusive data on economic cost reduction. The reasons are related to the few patients involved in the studies dedicated to this topic, to the different clinical settings, different modalities of provision and funding of PC, and different timing of PC implementation. PC was not shown to reduce mortality nor hospital readmissions in randomized trials. The unanswered questions will be clarified only in larger studies, defining specific clinical settings, goals to achieve and standardizing the provision and funding modalities in the different Abstract: [https://bit.ly/3bkbdo8](https://bit.ly/3bkbdo8)

N.B. Italian language article.

Related:

- *GIORNALE ITALIANO DI CARDIOLOGIA*, 2020;21(4):272-277. ‘Selection criteria to palliative care implementation in advanced heart failure.’ Barriers to implementation exist: perception that palliative care is opposite to "life-prolonging" therapies or is involved only in cancer disease and in end of life, prognostic difficulties in advanced heart failure, comorbidities, discrepancy between patient-reported symptom burden and objective measures of disease severity. This is why it is necessary to focus on patient and caregivers "needs" instead of exclusively numerical-objective measures, in order to emphasize clinical but also psychological, existential and spiritual elements contributing to quality of life. It is important to recognize triggers to initiate a PC approach… Abstract: [https://bit.ly/3abaxBn](https://bit.ly/3abaxBn)

N.B. Italian language article.

Experiences with end-of-life care with a left ventricular assist device: An integrative review

*HEART & LUNG* | Online – 18 March 2020 – This article demonstrates that patients with a left ventricular assist device, their caregivers, and providers, have many unmet needs regarding education and support through end-of-life (EoL) processes. Patients and their caregivers often feel confused and frustrated about the lack of information they have regarding what will occur during EoL processes. Providers of pa-
Patients with an left ventricular assist device (LVAD) have varying opinions regarding how to care for patients with an LVAD, and many have ethical issues regarding withdrawal of the device. More rigorous studies are needed to have a more fully comprehensive understanding regarding EoL with an LVAD. There is a great need for more provider education on this topic. Decision-making aides about EoL could also be beneficial, and have already been developed related to the decision whether to implant an LVAD. **Abstract:** [https://bit.ly/2y03oFL](https://bit.ly/2y03oFL)

Noted in Media Watch 25 February 2019 (#603, p.11):

- **JOURNAL OF PALLIATIVE MEDICINE** | Online – 22 February 2019 – ‘Top ten tips palliative care clinicians should know about caring for patients with left ventricular assist devices.’ Left ventricular assist devices (LVADs) can improve both the quantity and quality of life for those suffering with advanced heart failure (HF). Palliative care (PC) clinicians are being asked with increasing frequency to assist HF teams to manage patients with LVADs in the pre-implantation, post-operative, and end-of-life (EoL) settings, although not all PC providers feel comfortable with this technology. This article seeks to improve PC providers’ knowledge of LVADs and will prepare PC teams to counsel and support LVAD patients and their families from pre-implantation to the EoL. **Abstract:** [http://bit.ly/2E54zmN](http://bit.ly/2E54zmN)

**Implementing “goals-of-care” discussion and palliative care referral for patients with advanced lung cancer: An outpatient-based pilot project**

**INTERNAL MEDICINE JOURNAL** | Online – 23 March 2020 – A single-centre prospective audit reviewing goals-of-care (GoC) form completion and palliative care (PC) referrals in an oncology clinic was undertaken with the aim of increasing GoC completion and PC referrals for patients with advanced lung cancer. Participating physicians attended a communication skills course and then received a communication-priming interventions. Clinico-pathological factors associated with GoC completion and PC referral were explored. 84 patients receiving palliative treatment for advanced lung cancer were enrolled. The intervention improved GoC completion, however this was not sustained in a follow-up audit and there was no change in PC referral rate. **Abstract:** [https://bit.ly/3aep9jy](https://bit.ly/3aep9jy)

**Quality indicators of palliative care for acute cardiovascular diseases**

**JOURNAL OF CARDIOLOGY** | Online – 19 March 2020 – Although recent attention to palliative care (PC) for patients with cardiovascular diseases has been increasing, there are no specific recommendations on detailed PC practices. In this study, the authors developed 21 quality indicators, which were categorized into 2 major domains and 7 sub-categories. Among the initial 32 indicators, consensus was initially reached on total 23 indicators (71.8%), which were then summarized into 21 measures by selecting relatively feasible time variations. The major domains were “symptom palliation” and “supporting the decision-making process.” Seven sub-categories included “presence of PC team,” “patient-family relationship,” “multidisciplinary team approach,” “policy of approaching patients,” “symptom screening and management,” “presence of ethical review board,” “collecting and providing information for decision-maker,” and “determination of treatment strategy and the sharing of the care team’s decision.” **Abstract (w. list of references):** [https://bit.ly/3biSOrL](https://bit.ly/3biSOrL)

**Does receipt of recommended elements of palliative care precede in-hospital death or hospice referral?**

**JOURNAL OF PAIN & SYMPTOM MANAGEMENT**, 2020;59(4):778-786. Palliative care (PC) aligns treatments with patients’ values and improves quality of life, yet whether receipt of recommended elements of PC is associated with end-of-life (EoL) outcomes is understudied. Of 402 decedents [i.e., the patient population studied], 67 (16.7%) died in hospital, and 168 (41.8%) had hospice referral. Among elements of PC, only goals-of-care (GoC) discussion was associated with in-hospital death and hospice referral. Specialty PC consult was associated with a lower likelihood of in-hospital death. Understanding the causal pathways of GoC discussions may help build primary PC interventions to support patients near the EoL. **Abstract (w. link to references):** [https://bit.ly/2UFo6Cu](https://bit.ly/2UFo6Cu)
Challenges in the provision of end-of-life and palliative care to ethnic Nepali refugees

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 20 March 2020 – After over a decade of resettlement of ethnic Nepali refugees in the U.S., a significant population of seriously ill refugees will require palliative care (PC) and hospice care. The refugee experience and culturally specific factors affect the end-of-life care (EoLC) of this population. Challenges in the EoLC of Nepali refugees include challenges related to social and health inequities such as significant chronic respiratory disease burden, lack of protocols for deferral of illness disclosure, lack of support for group decision-making, unfamiliarity with spiritual, religious and traditional health practices and difficulty with cross cultural communication. Culturally competent care of ethnic Nepali refugees can be accomplished through respectful exploration of patients’ and families’ preferences regarding the challenges identified. This article presents recommendations which can guide primary and specialist PC for this population. Abstract (w. link to references): https://bit.ly/3bfSzhe

Bereavement accommodations in the classroom: Experiences and opinions of school staff

JOURNAL OF SCHOOL HEALTH, 2020;90(3): 165-171. Bereaved children often struggle in the school environment and school personnel often feel inadequately prepared to support them. This pilot study explored the experiences and opinions of school staff regarding approaches to addressing the needs of bereaved students in the classroom. Most participants (93%) reported interacting with bereaved students and: 1) Providing emotional support; 2) Making classroom accommodations; 3) Collaborating with the family/community; and, 4) Referring the student for counseling. Teachers encountering grieving students would welcome a templated bereavement plan to help meet students’ needs. Such a plan would allow staff to become more knowledgeable about grief and provide guidance for developing specific strategies to accommodate grieving students both emotionally and academically. Abstract: https://bit.ly/33DkwNc

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

Back Issues of Media Watch @ http://bit.ly/2ThijkC
Managing haematology and oncology patients during the COVID-19 pandemic: Interim consensus guidance

MEDICAL JOURNAL OF AUSTRALIA | Online – 20 March 2020 – The COVID-19 pandemic presents a challenge of global reach and significance, which is unprecedented in the era of modern haematology and oncology. The authors present interim COVID-19 guidance for clinicians caring for patients with cancer, who may be particularly vulnerable both to severe COVID-19 disease, and to the potential impact of the pandemic on the provision of cancer investigations and treatment. This is a rapidly-evolving situation, and the authors emphasise again that clinicians must regularly review and implement institutional, local, state-wide and federal/national policies, modifying or adapting the suggestions provided here as needed. Finally, given the potential severe impact of COVID-19 disease on people with cancer, the authors propose that oncologists and haematologists advocate for the timely application of public health measures or treatments that might contain, delay or mitigate the spread of COVID-19 disease. Full text: [https://bit.ly/2UfG13H](https://bit.ly/2UfG13H)

Response and role of palliative care during the COVID-19 pandemic: A national telephone survey of hospices in Italy

MEDRxIV | Online – 20 March 2020 – Sixteen Italian hospices, purposively sampled according to COVID-19 risk into high (more than 25 COVID-19 cases per 100,000 inhabitants), medium (15-25 cases per 100,000), and low risk (fewer than 15 cases per 100,000) regions. Two high risk hospices had experienced COVID-19 cases among both patients and staff. All hospices had implemented policy changes, and several had rapidly implemented changes in practice including transfer of staff from inpatient to community settings, change in admission criteria, and daily telephone support for families. Concerns included scarcity of personal protective equipment, a lack of hospice-specific guidance on COVID-19, anxiety about needing to care for children and other relatives, and poor integration of palliative care (PC) in the acute setting. The hospice sector is capable of responding flexibly and rapidly to the COVID-19 pandemic. Governments must urgently recognise the essential contribution of hospice and PC to the COVID-19 pandemic, and ensure these services are integrated into the healthcare system response. Abstract: [https://bit.ly/2vKoWWa](https://bit.ly/2vKoWWa)

Palliative care in Bologna during the COVID-19 crisis

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE | Online – 22 March 2020 – Dr. Danila Valenti, Medical Director of UO Rete delle Cure Palliative, a palliative care unit in Bologna, northern Italy, explains some of the main challenges facing healthcare professionals during the Coronavirus crisis and shares advice for others who are approaching a similar situation in their country. Blog: [https://bit.ly/39dlfpJ](https://bit.ly/39dlfpJ)

N.B. Click on pdf icon to view full text.
EMERGENCY MEDICINE

caring for Emergency Department patients with confirmed or suspected COVID-19 at the COVID-19 pandemic. The group is preparing to provide end-of-life care for an unknown number of people, in addition to the palliative care community’s pre-existing workload of seriously unwell patients, and their families, for whom this pandemic will generate significant physical and psychological distress. Full text: https://bit.ly/3bkBany

N.B. Links to the member organizations of the working group embedded in the text of the Insight article.

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION | Online – 27 March 2020 – ‘The importance of addressing advance care planning and decisions about do-not-resuscitate orders during novel Coronavirus 2019 (COVID-19).’ The COVID-19 pandemic is challenging healthcare systems worldwide and raising important ethical issues, especially regarding the potential need for rationing healthcare in the context of scarce resources and crisis capacity. Even if capacity to provide care is sufficient, one priority should be addressing goals-of-care in the setting of acute life-threatening illness, especially for patients with chronic, life-limiting disease. Clinicians should ensure patients receive care they want, aligning the care delivered with patients’ values and goals. Full text: https://bit.ly/2wMhZnU

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 March 2020 – ‘What should palliative care’s response be to the COVID-19 epidemic?’ Widespread transmission of COVID-19 in the U.S. could translate into large numbers of people needing medical care at the same time. This will push many health systems to the point of rationing limited resources such as ICU beds and life-sustaining machinery, as has occurred in Italy. Patients and their families at the peak of the pandemic will face symptoms, emotional distress, and decision-making in the face of uncertainty and limited options. No one is more prepared to handle these needs than providers on palliative care (PC) consult teams. However, PC consult teams are themselves a limited resource. Full text: https://bit.ly/2xtZkxh

SWISS MEDICAL WEEKLY | Online – 24 March 2020 – ‘COVID-19 pandemic: Palliative care for elderly and frail patients at home and in residential and nursing homes.’ Older people ... are at highest risk for severe and fatal disease. Severe illness with an uncertain outcome and end-of-life situations call for good palliative care (PC)... The Association for Geriatric Palliative Medicine (FGPG) promotes the integration of a PC approach and skills into the care of elderly and very elderly people – both in the inpatient setting and at home. The current pandemic and the publication of the SAMS Guidelines “COVID-19 pandemic: Triage for intensive-care treatment under resource scarcity” have prompted the FGPG to prepare recommendations for practice. Full text: https://bit.ly/3dvR6Fi

Resources relevant to palliative care & COVID-19:

The International Association for Hospice & Palliative Care has put together a list of resources relevant to palliative care and COVID-19, with links to websites and documents published by academia, civil society organizations, member states and special agencies of the United Nations. Download/view at: https://bit.ly/2QO1q1t

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Closing the Gap Between Knowledge & Technology

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Parent moral distress in serious pediatric illness: A dimensional analysis

NURSING ETHICS | Online – 5 March 2020 – Moral distress is an important and well-studied phenomenon among nurses and other healthcare providers, yet the conceptualization of parental moral distress remains unclear. To promote child and family best interest and minimize harm, a nuanced understanding of the moral, existential, emotional, and spiritual impact of serious pediatric illness is needed. Three dimensions emerged from the literature surrounding parent moral distress: 1) An intrapersonal dimension; 2) An interpersonal dimension; and, 3) A spiritual/existential dimension. The overarching theme is that parents experience relational solace and distress because of the impact of their child’s illness on relationships with themselves, their children, family, healthcare providers, their surrounding communities, and society. Elucidating this concept can help nurses and other professionals understand, mitigate, or eliminate antecedents to parental moral distress. The authors discuss how this model can facilitate future empirical and conceptual bioethics research, as well as inform the manner in which healthcare providers engage, collaborate with, and care for families during serious pediatric illness. Parent moral distress is an important and complex phenomenon that requires further theoretical and empirical investigation. The authors provide an integrated definition and dimensional schematic model that may serve as a starting point for future research and dialogue. Abstract (w. list of references): https://bit.ly/2WxDZxk

Supportive care needs of patients with head and neck cancer referred to palliative medicine

OTOLARYNGOLOGY: HEAD & NECK SURGERY | Online – 17 March 2020 – Patients with head and neck cancer (HNC) face a unique set of unmet needs. A subset of these patients experience symptom control challenges related to their disease burden and treatments. A multidisciplinary approach involving palliative medicine is underutilized but crucial to identify and address these concerns. There is limited information on palliative integration with head and neck oncology. Patients with HNC [i.e., the patient population studied] who were referred to palliative medicine are burdened by multiple physical, psychological, substance use, and social challenges. The authors recommend comprehensive cancer-specific screening … to triage patients to appropriate supportive care services. Palliative care is one of many services that these patients may need, and it should be utilized at any point of the disease trajectory rather than reserved for end-of-life care. Abstract (w. list of references): https://bit.ly/39fScSi

Noted in Media Watch 9 October 2017 (#533, p.15):

- OTOLARYNGOLOGY: HEAD & NECK SURGERY | Online – 3 October 2017 – Training otolaryngologists in palliative care delivery... Abundant evidence has demonstrated the beneficial effect for the early incorporation of palliative care (PC) in the treatment paradigm for patients with chronic diseases and malignancies, with findings supporting its positive effect on patients’ quality of life as well their survival. Particularly for otolaryngologists, the unique morbidities of head and neck cancer make their patients especially vulnerable and even more in need of the support and benefits that can come from PC. Training otolaryngologists to develop their own “primary PC competencies” is key for improving our patients’ outcomes. Abstract (w. list of references): https://bit.ly/3ag23ZJ

N.B. Additional articles on PC for patients living with head and cancer noted in 1 May 2017 issue of Media Watch (#510, p.15).

Hospice social workers’ perception of being valued by the interdisciplinary team and the association with job satisfaction

SOCIAL WORK IN HEALTH CARE | Online – 18 March 2020 – Being valued and respected by colleagues is an important contributor to job satisfaction in hospice and other healthcare settings. This study examine: 1) The degree to which hospice social workers feel valued by other members of the interdisciplinary team; and, 2) Whether this is associated with job satisfaction. A non-probability sample of 203 hospice social workers completed an online survey assessing job satisfaction, perception of feeling valued by each of the professionals on the interdisciplinary hospice team, interdependence of team members, and

Cont.
professional and personal characteristics. The final regression model for intrinsic job satisfaction included feeling valued by doctors and by other social workers and interdisciplinary interdependence. The final model for extrinsic job satisfaction did not include any of the perception of feeling valued by others on the interdisciplinary team, although interdependence and the number of social workers at the hospice were significant in this model. Reasons for the difference in these models and the practice and policy implications are discussed. **Abstract:** [https://bit.ly/3aa9Xnf](https://bit.ly/3aa9Xnf)

Noted in Media Watch 25 March 2019 (#607, p.12):

- **SOCIAL WORK IN HEALTH CARE** | Online – 19 March 2019 – 'Sitting with silence: Hospital social work interventions for dying patients and their families.' Controversy around hospital end-of-life (EoL) care highlights the vulnerability of dying patients and their families. Little is known about how social workers provide support and intervention at the EoL in the hospital. Eight hospital social workers provided qualitative descriptions of their clinical practice for adult patients and their families. Highlighting a theoretical orientation towards a person-in-environment approach, social workers develop unique interventions to contribute to multidisciplinary care. Findings emphasize the need to prepare social work students and clinicians for the reality of working with EoL issues. **Abstract:** [http://bit.ly/2Y9jcyC](http://bit.ly/2Y9jcyC)

N.B. Additional articles on the role of social workers in EoL care noted in this issue of Media Watch.

**The oldest old: The newest focus in end-of-life care?**

**SWISS MEDICAL WEEKLY** | Online – 22 March 2020 – Hug and colleagues examine the differences between the oldest old and younger patients in terms of the frequency of various EoL decisions such as intensified alleviation of pain and other symptoms and, most notably, withholding and withdrawing life-sustaining treatments.¹ This study is time-relevant as it is an inescapable truth that we are being confronted with a rapidly ageing population in many countries around the world. Already more than half of all Swiss deaths concern people over the age of 80, with a further increase expected in the future. These growing numbers of people also have increasingly long trajectories of health decline – both physical and cognitive – and of chronic and degenerative illness progression, depending on their specific afflictions. Needless to say, this is putting a high strain and pressure on the medical healthcare system as well as on society and our communities to provide adequate care for our oldest old. Not only is throwing more professionals at the problem not a feasible solution, but also the number of family caregivers available to every older person with healthcare needs is set to dwindle in the near future. Older people living with serious illness and multiple old age related co-morbidities are thus regarded as a group in a highly vulnerable position when it comes to their medical care and decision-making at the EoL. Download/view full text at: [https://bit.ly/2WCjsHW](https://bit.ly/2WCjsHW)


N.B. Click on pdf icon to access full text.

Noted in Media Watch 24 September 2018 (#582, p.12):

- **JOURNAL OF PALLIATIVE CARE** | Online – 19 September 2018 – ‘Clinical phenomenology and characteristics of centenarians in hospice.’ As the population of centenarians is projected to increase, understanding their unique end-of-life (EoL) needs will be important to inform delivery of quality EoL care. Seventeen centenarians [i.e., the hospice patient population studied] had an average age of 102 years. The most common hospice admission diagnosis was dementia (35%). Slightly less than half resided in nursing homes on admission, although death occurred most frequently in a nursing home. Centenarians were generally able to remain out of the hospital at their time of death. **Abstract** ([w. list of references]): [https://bit.ly/2GGeSoi](https://bit.ly/2GGeSoi)

Cont.
Noted in Media Watch 9 October 2017 (#533, pp.5-6):

- **BMC GERIATRICS** | Online – 26 September 2017 – ‘Dying comfortably in very old age with or without dementia in different care settings: A representative “older old” population study.’ Death not occurring until the tenth decade or later is becoming increasingly common, but dying in advanced old age is still rarely described. This study provides evidence to inform service planning to support very old people to die comfortably. Nearly half of the study’s representative sample of very old people experienced at least three symptoms during their final illness. Of the majority still living at home when last interviewed, those receiving support more than once a week were more likely to move before they died and less likely to be described as dying comfortably. **Full text:** [https://bit.ly/3dmGb0B](https://bit.ly/3dmGb0B)

**Assisted (or facilitated) death**

Representative sample of recent journal articles:

- **CANADIAN JOURNAL OF ANESTHESIA** | Online – 23 March 2020 – ‘A request for directed organ donation in medical assistance in dying.’ The authors outline a case of a patient wishing to direct their organ donation after receiving medical assistance in dying (MAiD). This case challenges current thinking, guidance, and rules about directed organ donation. The authors outline some ethical considerations that help frame this case and guide physicians in future cases and, recommend the following principles and guidance: 1) The assessment for MAiD eligibility is guided by legislation and remains completely independent of the assessment for donation; 2) If the patient is eligible for MAiD, the assessment for medical suitability to donate should proceed; 3) For medically suitable patients wishing to direct their donation, the assessors for MAiD should be notified by the patient themselves or the other assessor; 4) Two questions should then be considered by the patient and the assessors in an attempt to exclude coercion: If donation were not possible, would the patient still request MAiD? [and] If directed donation were not possible, would the patient still request MAiD?; 5) The authors conclude that if the MAiD assessors feel that answers to these questions do not indicate coercion, and the patient remains eligible, they should be permitted to direct their organ donation respecting the principles of agency and autonomy; and, 5) The authors also advise organ donation committees to constantly revisit every mechanism to ensure that every patient feels free up to the last moment to change their mind and respect their autonomy of choice if they meet requirements for donation. **Full text:** [https://bit.ly/2Ug83MA](https://bit.ly/2Ug83MA)

- **RIVISTA DI PSICHIATRIA**, 2020;55(2):119-128. ‘Euthanasia and physician-assisted suicide for patients with depression: Thought-provoking remarks.’ Euthanasia and medical assistance in dying entail daunting ethical and moral challenges, in addition to a host of medical and clinical issues, which are further complicated in cases of patients whose decision-making skills have been negatively affected or even impaired by psychiatric disorders. The authors closely focus on clinical depression and relevant European laws that have over the years set firm standards in such a complex field. Pertaining to the mental health realm specifically, patients are required to undergo a mental competence assessment in order to request aid in dying. The way psychiatrists deal and interact with decisionally capable patients who have decided to end their own lives, on account of sufferings which they find to be unbearable, may be influenced by subjective elements such as ethical and cultural biases on the part of the doctors involved. Moreover, critics of medical aid in dying claim that acceptance of such practices might gradually lead to the acceptance or practice of involuntary euthanasia for those deemed to be nothing more than a burden to society, a concept currently unacceptable to the vast majority of observers. Ultimately, the authors conclude, the key role of clinicians should be to provide alternatives to those who feel so hopeless as to request assistance in dying, through palliative care and effective social and healthcare policies for the weakest among patients: lonely, depressed or ill-advised people. **Full text:** [https://bit.ly/39e9AqO](https://bit.ly/39e9AqO)

**N.B.** English language article.

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**Media Watch: Access Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.16.
Publishing Matters

Thousands of Australian academics on the editorial boards of journals run by predatory publishers

LEARNED PUBLISHING | Online – 19 March 2020 – A total of 966 allegedly “predatory” open access publishers were examined to determine the nature of their ethical or unethical practices and the extent to which Australian academics were included on the editorial boards of their journals. An estimated 4,000 Australian academics (ca. 7% of the academic population) are on these journal boards. Of the publishers, 240 proved to be overtly fraudulent, the ethical status of the others remaining unresolved. About 86% of the Australian academics identified appeared on the editorial boards of journals belonging to those 240 publishers. Despite two decades of advocacy from librarians, there remains widespread ignorance of the existence of such fraudulent publishers, and more severe action is required. Reform proposals include naming the publisher in all references and in academic profiles and curriculum vitae. Universities are encouraged to take responsibility for publishing journals that replace those currently causing the problem. Institutions are urged to augment their current warnings and advice with formal policies, which will probably require a blacklist of unacceptable publishers. New formal policies for dealing with predatory publishers are currently being developed in some Australian universities.


Noted in Media Watch 19 March 2018 (#555, p.15):

- UNIVERSITY AFFAIRS | Online – 5 March 2018 – ‘Poor quality, predatory conferences prey on academics.’ Many publishers of deceptive or poor-quality academic journals have created a big sideline business organizing equally questionable academic conferences. Yet some professors don’t seem to be getting the message to stay away. McGill University professor Eduardo Franco discovered last year that OMICS International, one of these publishers, listed 220 McGill professors whom the company claimed had served as “editors, contributors and speakers” for OMICS journals and conferences. Most of the 220 McGill professors listed on the OMICS site likely had nothing to do with the company and didn’t know that the company was using their names in this way. Full text: [https://bit.ly/2JhkTnn](https://bit.ly/2JhkTnn)

N.B. OMICS International’s publications include the Journal of Palliative Care & Medicine.

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.

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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

[Scroll down to ‘Media Watch: Updates’]


[Scroll down to ‘Media Watch by Barry Ashpole’, also ‘Media Watch: Behind the Scenes’ at: http://bit.ly/2MwRRAU ]

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

[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): HTTP://BIT.LY/300WMRT


U.K. | Omega, the National Association for End-of-Life Care: http://bit.ly/2MvVir1

South America


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Barry R. Ashpole, Ontario CANADA e-mail: barryashpole@bell.net