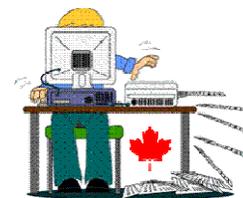


Media Watch...

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

Analysis suggests the need for public education concerning the end-of-life (EoL) process, and for changes within the healthcare system to improve communication, to improve understanding of the needs of the terminally ill, and to provide more instruction to family caregivers to help them understand EoL.

'Regrets of family caregivers in Israel about the end of life of deceased relatives' (p.9), in *Aging & Mental Health*.

U.S.A.

Palliative care linked to a 10% drop in ICU use for terminal patients

BECKER'S HOSPITAL REVIEW | Online – 9 January 2020 – Offering palliative care (PC) services to patients with terminal conditions can help reduce their use of the intensive care unit, a study published in *JAMA Network Open* shows.¹ Researchers studied 51 hospitals in New York that either did or did not implement a PC program between 2008 and 2014. They examined data for 73,370 patients who died during their hospitalizations. Of the total number of patients included in the study, 51.3% received care in hospitals that implemented PC services, and 48.7% received care in a hospital that did not. Researchers found that patients who received the PC services were less likely to be admitted to the ICU than patients admitted to the same hospitals before the PC program was imple-

mented. The implementation of PC programs was associated with a 10% reduction in ICU use during hospitalizations where the patients died, compared to hospitals that did not implement PC services. <http://bit.ly/36luv4O>

Specialist Publications

'You're in...but this service requires drug testing' (p.5), in *American Journal of Bioethics*.

'Palliative care use in patients with acute myocardial infarction' (p.8), in *Journal of the American College of Cardiology*.

1. 'Association between the implementation of hospital-based palliative care and use of intensive care during terminal hospitalizations,' *JAMA OPEN NETWORK*, published online 8 January 2020. **Full text:** <http://bit.ly/2QBm0mz>

Cont.

Noted in Media Watch 16 December 2019 (#644, p.11):

- *JAMA OPEN NETWORK* | Online – 11 December 2019 – ‘**Assessment of variability in end-of-life care delivery in intensive care units in the U.S.**’ Overall, 1 of 5 decedents in the U.S. is admitted to an intensive care unit (ICU) before death. This cohort study [of 1,536 decedents within a national quality improvement collaborative] describes structures, processes, and variability of the end-of-life care (EoLC) delivered in ICUs. EoLC delivery varied substantially, and the patterns of care observed suggest that units can be characterized as higher and lower performing. To achieve optimal care for patients who die in an ICU, future research should target unit-level variation and disseminate the successes of higher-performing units. **Full text:** <http://bit.ly/2YKNWGP>

Noted in Media Watch 11 March 2019 (#605, p.9):

- *INTENSIVE CARE MEDICINE* | Online – 7 March 2019 – ‘**Eight things we would never do regarding end-of-life care in the ICU.**’ As intensivists from three distinct regions of the world [i.e., the U.S., France, Israel] with different cultural backgrounds, the authors believe it relevant in this rapidly emerging period of healthcare to share thoughts among clinicians providing end-of-life care (EoLC) in the intensive care unit. This article presents the authors’ vision of eight top-tier concepts that should be embraced to usher in the best EoLC for all patients. The authors realize that not everyone will agree with these points and anticipate that our “eight things” will stimulate healthy discussion and debate. **Abstract (w. list of references):** <http://bit.ly/2XHEB1L>

N.B. Selected articles on EoLC in ICU noted in 7 October 2019 issue of Media Watch (#634, p.9).

Medicare Advantage plans offering palliative care quadrupled for 2020

HOSPICE NEWS | Online – 9 January 2020 – A rising number of Medicare Advantage plans are offering home-based palliative care (PC) as a supplemental benefit. This year, 61 plans offer a PC benefit compared to 15 during 2019, a new Duke University report indicates.¹ Hospices provide about 50% of home-based PC in the U.S. according to the Center to Advance Palliative Care,² and the number of providers that are diversifying their services lines to include PC continues to increase. Through Medicare Advantage, the U.S. Centers for Medicare & Medicaid Services contracts with private insurance companies to provide coverage for Medicare beneficiaries. Law requires Medicare Advantage plans to cover all of the services offered by traditional Medicare, but also allows for certain supplemental benefits. Historically these benefits were very limited, but the Creating High-Quality Results & Outcomes Necessary to Improve Chronic Care Act, passed by Congress in 2018, expanded the range of those benefits to include programs to address some social determinants of health as well as home-based PC. The legislation also permitted Medicare Advantage plans to target specific populations among their enrollees to receive these benefits – such as those with serious illness or high-health care utilization – rather than offering the same benefits to all enrollees. <http://bit.ly/2Nc6ify>

1. ‘Improving serious illness care in Medicare Advantage: New regulatory flexibility for supplemental benefit,’ Duke University, December 2019. **Download/view at:** <http://bit.ly/39ZFNU8>
2. ‘Mapping community palliative care: A snapshot,’ Center to Advance Palliative Care, December 2019. [Noted in 23 December issue of Media Watch (#645, p.3)] **Download/view at:** <http://bit.ly/2tswrzB>



Current thinking on palliative and end-of-life care for patients living with intellectual and developmental disabilities: <http://bit.ly/300WMRt>

International

Charities call on government to “find its heart” and change benefit laws for terminally ill patients

U.K. (England, Northern Ireland & Wales) | inews.co.uk (London) – 11 January 2020 – Charities have urged the government to “find its heart” and change the law surrounding welfare support of terminally ill patients. They estimate 2,000 people have died over the past six months while waiting for benefit payments. As it stands, benefit claimants can only get their welfare support fast-tracked if a doctor deems they have six months to live. The Department for Work & Pensions promised a “fresh and honest evaluation” of the benefit system in summer. However, the Marie Curie and the Motor Neuron Disease Association groups claim no progress has been made in this time. The charities argue the current six-month rule prohibits dying people to “fast and easy” access to benefits. They are calling on the government to allow “dying people to get the support they need and die with dignity.” In England, Scotland and Wales there are 10 people who die each day before receiving their Personal Independence Payment – funds de-

signed to help those with long-term health problems and disabilities. <http://bit.ly/37UyVFO>

Specialist Publications

‘A sense of security in palliative homecare in a Norwegian municipality; dyadic comparisons of the perceptions of patients and relatives: A quantitative study’ (p.6), in *BMC Palliative Care*.

‘Nursing home staff’s perspective on end-of-life care of German nursing home residents: A cross-sectional survey’ (p.6), in *BMC Palliative Care*.

‘Primary care physicians’ role in coordinating medical and health-related social needs in eleven countries’ (p.7), in *Health Affairs*.

“‘Find out what they lack, try to provide’”: A qualitative investigation of palliative care services adapted to local need in a low-resource setting’ (p.11), in *Journal of Palliative Medicine*.

Noted in Media Watch 15 July 2019 (#622, p.6):

- U.K. (England, Northern Ireland & Wales) | *The Guardian* (London) – 11 July 2019 – **‘Benefits system for terminally ill people to be reviewed.’** The work and pensions secretary has announced a review of the benefits system for terminally ill claimants. The system has been heavily criticised by charities for denying benefits in some cases to people who have died shortly afterwards and asking insensitive questions such as to name a date when they expect to die. The rules were often seen as favouring those living with cancer when other illnesses can also limit life. The review will involve three strands of research, including hearing from claimants and charities about their experiences, consideration of international evidence, and an analysis of current performance.. <http://bit.ly/2SbnnXX>



Indigenous peoples present unique challenges in the provision and delivery of palliative and end-of-life care

A selection of articles focusing on the critical importance of sensitivity to cultural distinctions and linguistic differences, and respect for beliefs, values and end-of-life practices, are highlighted in the current issue of the Association’s newsletter. **Download/view at (scroll down to ‘Media Watch: Indigenous Peoples’):** <http://bit.ly/2sMI2JY>

Specialist Publications

Survey of paediatricians found them to be involved in advance care planning: Are we there yet?

ACTA PAEDIATRICA | Online – 9 January 2020 – Research studies have consistently found that communication between physicians and minors and their relatives was complex. For example, important discussions about future care and medical decision-making were often not initiated until a medical crisis occurred. Advance care planning (ACP) has been promoted as a successful strategy that generates such communication. It is a multistage process of interaction between patients, their relatives and healthcare professionals. It is also a voluntary process of discussion and review, which enables patients to express their feelings, values and wishes concerning their future care and treatment. Adult studies have shown that ACP increased congruence in treatment preferences between patients and medical staff and increased the likelihood that patients' preferences were respected. Care that more adequately addresses patients' needs and preferences may result in improved quality

of life and greater satisfaction with the care itself. International guidelines and medical organisations, such as the American Academy of Pediatrics, the Institute of Medicine and the World Health Organization, strongly recommend ACP for adults and children. However, minors have been broadly neglected in existing ACP programmes and ACP research, which implies that they may be denied the possible benefits of ACP that have been reported by adult studies. **Full text:** <http://bit.ly/2NcJWug>

Publishing Matters

'Publishing habits and perceptions of open access publishing and public access amongst clinical and research fellows' (p.14), in *Journal of the Medical Library Association*.

Related:

- *JOURNAL OF PAEDIATRICS & CHILD HEALTH* | Online – 3 January 2020 – **'Treatment limitation and advance planning: Hospital-wide audit of paediatric death.'** The authors examine paediatric deaths following withdrawal or withholding of medical treatment (WWMT) from a hospital-wide perspective and identify changes over a 10 year period. 101 deaths occurred in the inpatient setting in 2015-2016. Most followed WWMT and occurred in children with pre-existing chronic conditions. There was a shift to earlier discussions with parents regarding WWMT compared to 10 years prior. There was also increased paediatric palliative care (PPC) involvement, and a slightly greater proportion of children died outside of intensive care. **Abstract:** <http://bit.ly/2tBbWAV>

A new perspective on spiritual care: Collaborative chaplaincy and nursing practice

ADVANCES IN NURSING SCIENCE | Online – 9 January 2020 – Spirituality is a key focus and ethical obligation of nursing practice, but many nurses express uncertainty or discomfort with this aspect of their role. This article explores the domains of religion, spirituality, and culture as commonly conceptualized by chaplains, as a framework for nurses to provide spiritual care interventions to patients in acute care hospitals. Using anecdotes and illustrations from palliative care (PC) practice, this article discusses the enhanced benefits to patients and families when spiritual needs are addressed, with specialty-level chaplain interventions, primary spiritual interventions provided uniquely by nurses, or interventions that require the cooperation of both professions. Lessons learned from the inpatient PC team experience can also apply to chaplaincy and nursing care for patients in settings beyond the acute care hospital and in disciplines beyond PC. **Abstract:** <http://bit.ly/2NhHPVX>

N.B. Additional articles on spirituality in the context of PC care noted in 6 January 2020 issue of Media Watch (#647, p.8). Additional articles on the role of chaplaincy in PC noted in 6 May 2019 issue of Media Watch (#613, p.8).

You're in...but this service requires drug testing

AMERICAN JOURNAL OF BIOETHICS, 2020;20(1):78-80. Outpatient palliative care (PC) programs are becoming a new source of ethics consults pertaining to suspected drug diversion and parameters for the safe prescribing of pain medications. While expanding access to PC via the outpatient setting and simplifying pain management for patients is beneficial, these programs also contribute to a supply of drugs that can be diverted, misused or abused... Studies indicate that people with substance use disorders often divert pain medication from their friends or relatives, a complication in the outpatient palliative setting where family or friends frequently serve as caregivers for the patient. Chronic pain management thus becomes a balancing act for the care team; PC professionals question how to ensure end-stage or chronic patients receive the pain-relieving medication they need while not contributing to the possibility of drug diversion. **First page view (w. link to references):** <http://bit.ly/2Fy5NrD>

N.B. See 'Diverting opioid diversion: Does it justify randomly screening palliative care patients?' *American Journal of Bioethics*, 2020;20(1):71-72. **Access case report at:** <http://bit.ly/2MY51sj>

Noted in Media Watch 25 November 2019 (#641, p.10):

- *INNOVATION IN AGING* | Online – 8 November 2019 – 'End-of-life care during the national opioid crises: A national survey of hospice providers.' No national data exist on drug shortages, missing medications, opioid diversion, and opioid diversion prevention in hospice. The authors randomly selected 600 hospices to survey representatives about: 1) Care for patients/families with substance use disorder (SUD); 2) Drug shortages; 3) Instances of drug diversion; and, 4) Drug disposal practices. Half of the 371 hospices that responded were mid-sized (26-100 patients) and non-profit. On average, hospices have nearly one case of opioid diversion per quarter. Hospices are experiencing medication shortages and restrictions on medication disposal. **Abstract:** <http://bit.ly/37fv9Ho>

N.B. Additional articles on drug diversion in the hospice and PC settings noted in this issue of Media Watch.

Caregiver-reported barriers to quality end-of-life care in dementia with Lewy Bodies: A qualitative analysis

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 January 2020 – Dementia with Lewy Bodies (DLB) is one of the most common degenerative dementias in the U.S. Interview participants described multiple barriers to quality end-of-life (EoL) experiences in DLB, e.g., lack of recognition and knowledge of DLB, lack of education regarding what to expect, poor coordination of care and communication across healthcare teams and experiences, and difficulty accessing healthcare resources including skilled nursing facility placement and hospice. While many of these findings are consistent with published barriers to quality EoL care in dementia, DLB-specific EoL considerations include challenges obtaining a DLB diagnosis, lack of knowledge regarding DLB and resultant errors in care (e.g., administration of antipsychotics), difficulty accessing resources, particularly because of behavior changes in DLB, and waiting to meet Medicare hospice guidelines for dementia. More research is needed to identify DLB stages, recognition of EoL in DLB, factors that drive quality EoL experiences, and best practices for tailoring palliative approaches for DLB. **Full text:** <http://bit.ly/2SVEP5m>

Research literature on the intersection of dementia, spirituality, and palliative care: A scoping review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 7 January 2020 – Research gaps exist in understanding the intersection of dementia, spirituality, and palliative care (PC). The final sample consisted of 19 studies with the following themes: characterizing spiritual needs, preferences, and resources; characterizing palliative or spiritual care (SC); predicting provision of SC; and, assessing SC interventions. The majority of studies focused on long-term care (LTC) settings, grouped stages of dementia or did not specify dementia stage, and investigated interventions indirectly related to SC. Many studies were limited in sample size and in generalizability/ transferability and used less sophisticated research designs. Research across dementia, spirituality, and PC needs to examine distinct stages of dementia, settings beyond LTC, and formal SC interventions plus utilize rigorous study designs (e.g., randomized clinical trials). **Abstract (w. link to references):** <http://bit.ly/36BFGvU>

A sense of security in palliative homecare in a Norwegian municipality; dyadic comparisons of the perceptions of patients and relatives: A quantitative study

BMC PALLIATIVE CARE | Online – 11 January 2020 – This study shows both high and low values in patients' perceptions of security in the palliative homecare received, whereas there are no high scores from relatives. The patients scored the subjective importance of the care higher than palliative homecare received in one dimension and one aspect (continuity), whereas relatives' scores differed in all dimensions and aspects. When assessing the palliative care received, this study reveals that there was limited agreement within the patient-relative dyads on all three dimensions and on the aspect of coordination/cooperation. Studies about the sense of security in palliative homecare from the perspectives of patient-relative dyads are important as relatives often provide care and act as a spokesperson for the patient, but also because relatives themselves are in a stressful situation. What patients and relatives assess as important in palliative homecare can guide the further development of this area. The present study adds knowledge that can contribute to concrete aspects of security in palliative homecare. More studies with a larger sample are required to further develop the Quality from the Patients' Perspective Security instrument. **Full text:** <http://bit.ly/2NkFeL8>

Nursing home staff's perspective on end-of-life care of German nursing home residents: A cross-sectional survey

BMC PALLIATIVE CARE | Online – 3 January 2020 – Overall, more than one third of the participants of this study consider end-of-life (EoL) care of German nursing home residents rather poor. Germany is among the countries with the highest amount of EoL hospitalization in the western industrialised world. Hence, improvement needs to be made and one way may be to properly document detailed information on this topic in the form of advance directives. Another way of improving EoL care may be supporting the utilization of palliative care (PC) as well as spreading PC concepts. This may be reached through further training of nurses and physicians, but more research is needed to develop highly efficient and well evaluated trainings in the context of the German healthcare system. With better training and, in turn, expansion of the nurses' responsibilities as well as wider availability of PC and higher staffing, EoL medical care of German nursing homes may well improve. **Full text:** <http://bit.ly/2SRtvXM>

Related:

- *GERIATRICS & GERONTOLOGY INTERNATIONAL* | Online – 24 November 2019 – '**End-of-life care of nursing home residents: A survey among general practitioners in north-western Germany.**' Approximately seven out of 10 GPs considered that nursing home residents (NHR) are too often hospitalized during end of life (EoL), and more than half rated EoL care as "rather poor." GPs with a qualification in palliative medicine were even more critical. The fact that EoL hospitalizations of NHR are more common in Germany than in other Western countries, where palliative care (PC) is more widely available, underlines that healthcare professionals should critically assess when palliative approaches are required. GPs and nursing staff require more training in PC. **Full text:** <http://bit.ly/2ZTHoq2>

Medical student confidence in care of the dying and their family: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 9 January 2020 – The [U.K.] General Medical Council expects medical graduates to care for dying patients with skill, clinical judgement and compassion. U.K. surveys continually demonstrate low confidence and increasing distress amongst junior doctors when providing care to the dying. Fifteen eligible studies were included, demonstrating a diversity of assessment tools. Student confidence was low in provision of symptom management, family support, and psycho-spiritual support to dying patients. Eight interventional studies demonstrated increased post-interventional confidence. Lack of undergraduate exposure to dying patients and lack of structure within undergraduate palliative care curricula were cited as factors responsible for low confidence. This review clarifies the objective documentation of medical undergraduate confidence to care for the dying. Identifying where teaching fails to prepare graduates for realities in clinical practice will help inform future undergraduate palliative care curriculum planning. **Abstract:** <http://bit.ly/35CKNdV>

Electronic coordination for end-of-life care

BRITISH JOURNAL OF GENERAL PRACTICE, 2020;70(690):e20-e28. Quality palliative care depends on recording, sharing, and acting on patients' needs and preferences, such as their wishes about resuscitation and their preferred place of death. An electronic care coordination system known as KIS (Key Information Summary) was evaluated in Scotland using data from over 1,300 deceased patients. The study found that patients with a KIS record were twice as likely to die in the community, as they wished, rather than in hospital, and most had a record of their desired resuscitation status. Patients with frailty and dementia frequently had a KIS recorded a year or more before their death. **Full text:** <http://bit.ly/37Xqytf>

Influence of clinical context on interpretation and use of an advance care planning policy: A qualitative study

CMAJ OPEN | Online – 7 January 2020 – This study explored perspectives from 34 patients and 34 clinicians in 4 clinical settings (cancer, heart failure, renal failure and supportive living outpatient settings) to understand how context influences interpretation and application of advance care planning (ACP) processes. Themes common to all four contexts were lack of shared understanding between patients and clinicians, and a lack of consistent clinical process related to ACP. ACP understanding and process varied substantially between contexts. This variation seemed to be driven by differences in perceptions around disease burden and the nature of the physician-patient relationship. Provision of a system-wide policy and procedural framework alone was not found to be sufficient to form a standardized approach to ACP. Quality-improvement methods that consider local processes, gaps and barriers can help in developing a consistent, comprehensive process. **Full text:** <http://bit.ly/36HQA3z>

Primary care physicians' role in coordinating medical and health-related social needs in eleven countries

HEALTH AFFAIRS, 2020;39(1):124-132. Primary care physicians in the U.S., like their colleagues in several other high-income countries, are increasingly tasked with coordinating services delivered not just by specialists and hospitals but also by home care professionals and social service agencies. To inform efforts to improve care coordination, the 2019 Commonwealth Fund International Health Policy Survey of Primary Care Physicians queried primary care physicians in eleven high-income countries – Australia, Canada, France, Germany, The Netherlands, New Zealand, Norway, Sweden, Switzerland, the U.K., and the U.S. – about their ability to coordinate patients' medical care with specialists, across settings of care, and with social service providers.¹ Compared to physicians in other countries, substantial proportions of U.S. physicians did not routinely receive timely notification or the information needed for managing ongoing care from specialists, after-hours care centers, emergency departments, or hospitals. Primary care practices in a handful of countries, including the U.S., are not routinely exchanging information electronically outside the practice. Top-performing countries demonstrate the feasibility of improving two-way communication between primary care and other sites of care. The surveyed countries share the challenge of coordinating with social service providers, and the results call for solutions to support primary care physicians. **Abstract:** <http://bit.ly/36xMxGS>

1. 'Primary care physicians in U.S. struggle more to coordinate care and communicate with other providers but offer patients more health IT tools,' Commonwealth Fund International Health Policy Survey of Primary Care Physicians, December 2019. **Download/view at:** <http://bit.ly/2tH5Rmc>

Noted in Media Watch 31 March 2014 (#351, p.7):

- *INTERNATIONAL JOURNAL OF INTEGRATED CARE* | Online – 20 March 2014 – '**Integrated end-of-life care: The role of social services.**' If palliative care (PC) must be holistic, then it should include the social nature of the aid. Many of the effective solutions often required to adequately take care of each case are not health services, but rather social ones. If these social resources and benefits are not offered, it will mean greater costs for the health system and a dysfunctional use of the competences of healthcare professionals for tackling social needs that are better addressed by other types of professionals. Integration of social support in the provision of PC seems to be an efficient way to respond to the complex mix of needs of people in the end stage of their lives. **Full text:** <http://bit.ly/2QvPgL7>

Elements of social convoy theory in mobile health for palliative care: Scoping review

JMIR MHEALTH UHEALTH | Online – 6 January 2020 – Mobile health (mHealth) provides a unique modality for improving access to and awareness of palliative care (PC) among patients, families, and caregivers from diverse backgrounds. Some mHealth PC apps exist, both commercially available and established by academic researchers. However, the elements of family support and family caregiving tools offered by these early apps is unknown. This review highlights important information on the inclusion and functionality of social convoy members in mHealth apps for PC. Its findings suggest there is an emerging presence of apps for patients and convoy members receiving PC; however, there are many needs for developers and researchers to address in the future. Specifically, additional work is needed for apps that embrace a team approach to information sharing, target convoy-specific issues, promote access to PC, and are comprehensive of palliative needs. Furthermore, the inclusion of convoys in mHealth research is severely lacking and requires attention in the literature. Limitations and recommendations presented in this review may help guide future development of mHealth apps and scientific studies designed to support the needs of patients and convoy members in PC. **Full text:** <http://bit.ly/2ZZUphM>

Palliative care use in patients with acute myocardial infarction

JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY, 2020;75(1):113-117. Despite advances in pharmacological therapy and timely reperfusion, acute myocardial infarction (AMI) remains one of the leading causes of death in the U.S. Although the incidence of AMI has been decreasing with improvement in preventive strategies and medical therapy, in-hospital mortality has not changed in recent years. The lack of reduction in-hospital mortality has also been observed in the subset of patients with cardiogenic shock, which carries a remarkably higher incidence of in-hospital mortality... In patients with complex conditions, such as AMI, there has been increasing interest in integrating palliative care (PC), which might help alleviate the physical and psychological discomfort of patients and their families, and also assist in the transition of care after an intensive care unit stay. In the past decade, efforts have been mainly directed toward improving pharmacological therapies, adherence to medical therapy, timely reperfusion, and assessing short- and long-term outcomes in patients with AMI; however, studies have not focused on investigating the penetration (defined as the percentage of annual hospital admissions seen by the PC team) or PC in these patients. Using data from a large nationwide database, the authors examined the temporal trends and predictors of PC in hospitalizations for AMI. **First page view:** <http://bit.ly/2N5KKB1>

Noted in Media Watch 26 March 2018 (#556, p.10):

- *JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY*, 2018;71(12):1391-1394. **‘Palliative care education in cardiology.’** This is the first study to evaluate the quantity and quality of palliative care (PC) education in U.S. cardiology fellowship programs... Results demonstrate that PC skills are important to cardiologists in training and in practice, but cardiology fellowships currently offer incomplete education in essential PC competencies. This study shows that among crucial PC skill sets, symptom management and advance care planning are two of the least well represented in current cardiology training guidelines. To address these deficits, the authors propose the development of a task force to define standardized **Full text:** <http://bit.ly/37Qhg9P>



[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>

**Painting a rational picture during highly emotional end-of-life discussions:
A qualitative study of internal medicine trainees and faculty**

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 2 January 2020 – Physicians [i.e., study participants] depicted end-of-life (EoL) discussions as a process directed at painting a realistic picture of a clinical situation. By focusing their efforts on reaching a shared understanding of a clinical situation with patients/families, physicians self-delineated the boundaries of their professional responsibilities regarding EoL care (i.e., help with understanding, not with accepting or making the “right” decisions). Information sharing took precedence over emotional support in most physicians’ accounts of EoL discussions. However, the emotional impact of EoL discussions on families and physicians was readily recognized by participants. EoL discussions are complex, dynamic social interactions that involve multiple, complementary competencies. Focusing mostly on sharing clinical information during EoL discussions may distract physicians from providing emotional support to families and prevent improvements of EoL care delivered in acute care settings. **Abstract (w. list of references):** <http://bit.ly/2QSzs4d>

Regrets of family caregivers in Israel about the end of life of deceased relatives

AGING & MENTAL HEALTH | Online – 8 January 2020 – This article provides a comprehensive description of end-of-life (EoL) regrets and helps clarify the complexity of regrets, lack of regrets, and ambivalence concerning regrets, though the study is limited to one country. Analysis suggests the need for public education concerning the EoL process, and for changes within the healthcare system to improve communication, to improve understanding of the needs of the terminally ill, and to provide more instruction to family caregivers to help them understand EoL. A majority of caregivers [interviewed] expressed regret and about 20% expressed ambivalence involving both regret and denial of regret. Regrets pertained to care given, suffering experienced, and the caregiver’s behavior towards, and relationship with the deceased, including missing opportunities to express love and caring toward relatives. Caregivers viewed almost 30% of 75 administered life-sustaining procedures as misguided. Most regrets involved inaction, such as not communicating sufficiently, or not fighting for better care. **Abstract:** <http://bit.ly/2t4nGMj>

Life, love, hope, faith, and death – too complex for Likert

JOURNAL OF PALLIATIVE CARE | Online – 7 January 2020 – More research to examine factors contributing to healthcare disparities at the end of life (EoL) is greatly needed. This article outlines a failed attempt to quantify some of the motivators in medical decision-making for African American families faced with a decision to pursue or forego a percutaneous endoscopic gastrostomy in a loved one at the EoL. It explores the complexities of spirituality, history, culture, and death in the authors’ patient population in Charleston, South Carolina, where healthcare disparities are well-documented, and distrust has deep historical roots. It outlines the need for qualitative research, where the defining role of the researcher is to practice the paramount palliative skill of listening. **Abstract:** <http://bit.ly/2FuPjRp>

“I’d have to basically be on my deathbed”: Heart failure patients’ perceptions of and preferences for palliative care

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 January 2020 – Despite guidelines calling for the integration of palliative care (PC) into the management of heart failure (HF), PC services remain underutilized by this population. Patient preferences regarding delivery of and triggers for PC are unknown. Participants [in this study] frequently conflated PC with hospice; once corrected, they expressed variable preferences for primary versus specialist services. Proponents of primary PC cited continuity in care, HF-specific expertise, convenience, and cost, whereas advocates for specialist care highlighted expertise in symptom management and caregiver support, reduced time constraints, and a comprehensive approach to care. Triggers for specialist PC focused on late-stage manifestations of disease such as loss of independence and absence of disease-directed therapies. Study participants with HF demonstrated variable conceptions of PC and its relevance to their disease management. Patients with HF may misconceive PC is an option of last resort. **Abstract:** <http://bit.ly/2NngVmx>

Cont.

Noted in Media Watch 23 December 2019 (#645, p.6):

- *EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING* | Online – 16 December 2019 – ‘**Palliative care and heart failure: Can implementation science help where the evidence alone has failed?**’ Gaps between publication and the adoption of research into practice can take up to 17 years, with only 14% of original research ever applied for the benefit of patient care. It is imperative that we accelerate the translation of evidence into practice. In the case of progressive/advanced heart failure (HF) ... a palliative care (PC) approach integrated with conventional/active HF management has strong evidence for improved outcomes for patients in terms of quality of life, symptom burden, caregiver outcomes and reductions in health service costs. **Full text:** <http://bit.ly/2S6NRfz>

N.B. Additional articles on PC in HF noted in 16 December 2019 issue of Media Watch (#644, p.10).

Experiences of lesbian, gay, bisexual, and transgender patients and families in hospice and palliative care: Perspectives of the palliative care team

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 January 2020 – Lesbian, gay, bisexual, and transgender (LGBT) patients fear being open about their identities, not receiving equal or safe treatment, and having their family and surrogates disrespected or ignored by providers. Among [survey] respondents [i.e., 865 hospice and palliative care providers, including physicians, social workers, nurses and chaplains], 53.6% thought that lesbian, gay, or bisexual (LGB) patients were more likely than non-LGB patients to experience discrimination at their institution; 23.7% observed discriminatory care; 64.3% reported that transgender patients were more likely than non-transgender patients to experience discrimination; 21.3% observed discrimination to transgender patients; 15% observed the spouse/partner of LGBT patients having their treatment decisions disregarded or minimized; and 14.3% observed the spouse/partner or surrogate being treated disrespectfully. These findings provide strong evidence that LGBT patients and their families are more likely to receive discriminatory care as compared with those who are not LGBT. Advocacy and staff training should address barriers to delivering respectful and non-discriminatory care.

Abstract: <http://bit.ly/2tIQQRc>

Noted in Media Watch 21 October 2019 (#656, p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 13 October 2019 – ‘**Cultural humility: A way to reduce lesbian, gay, bisexual, transgender, and queer or questioning health disparities at the end of life.**’ The authors describe the limitations of cultural competency training and argue for healthcare systems to implement cultural humility training as a way to reduce lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ) health disparities at the end of life. Cultural humility training focuses on: 1) Individuals instead of their cultural groups; 2) Self-reflection; and, 3) Active listening. The authors assert that these align with the aims of healthcare systems and can be an essential tool in reducing LGBTQ health disparities. **Abstract:** <http://bit.ly/2plG9BA>

N.B. Additional articles on palliative and hospice care for LGBTQ people noted in this issue of Media Watch.

Therapeutic holding [in effective palliative care]

JOURNAL OF PALLIATIVE MEDICINE | Online – 8 January 2020 – Relationships of care for those facing illness are inherent to the practice of medicine. Palliative care (PC) provides interpersonal space to patients and families that helps them face serious illness and dying. The authors consider therapeutic holding uniquely critical in PC but see it as applying in varied forms throughout medicine. Its optimization requires a deep understanding of its nature. The authors use theoretical foundations of psychodynamic therapy, which uses the therapeutic relationship as its sole intervention, to identify the key elements of PC’s therapeutic holding. They draw together six major concepts to do so. Using a fairly typical case, the authors illustrate how a PC team that included a psychodynamic therapist created therapeutic holding. This case exemplifies how psychodynamic theory discerns and describes elements of PC’s therapeutic holding. The case further illuminates the important place of therapeutic holding in effective PC and shows how psychodynamic therapy can help. **Abstract:** <http://bit.ly/35Goxji>

“Find out what they lack, try to provide”: A qualitative investigation of palliative care services adapted to local need in a low-resource setting

JOURNAL OF PALLIATIVE MEDICINE | Online – 7 January 2020 – People in low- and middle-income countries with serious health problems rarely have access to palliative care (PC). Promising models of PC delivery have emerged in India despite widespread poverty and poor healthcare infrastructure. The authors explored structural and philosophical aspects of PC delivery in a low-resource setting: one spent six months as a participant-observer at Pallium India (PI), a non-governmental organization recognized for leadership in PC delivery in Kerala, India. The authors performed 73 interviews with patients, families, clinicians, staff, and volunteers, and observed 180 patient encounters. The majority of PC patients did not have cancer. Many had chronic diseases that were not immediately life-threatening. Services addressed a broad range of patients’ medical, psychological, social, and/or financial needs. PI employs an expansive definition of PC and adapts services to respond to patients’ diverse needs. This accessible, people-centered care is necessary in low-resource settings to alleviate multifaceted suffering caused by gaps in the healthcare system, poor social support, and poverty. **Abstract:** <http://bit.ly/2N7Unzi>



Noted in Media Watch 1 April 2019 (#608, p.4):

- INDIA | *The New Indian Express* (Chennai) – 29 March 2019 – ‘**Kerala Planning Board approves revised guideline on community-based palliative care projects.**’ A palliative management committee has been formed under each local body to ensure that the home care programme is being implemented successfully. Home care teams are directed to work closely with medical teams attending patients in the hospital. For self-evaluation of pain and palliative care (PC) projects in their respective areas, standing committees for health/education/welfare have been asked to include PC as a separate agenda during their meetings. And, district panchayats, municipalities, corporations and block panchayats are to ensure better PC initiatives at health institutions in their jurisdiction. <http://bit.ly/2FBkgTv>

Noted in Media Watch 11 February 2019 (#601, p.6):

- *BMC PALLIATIVE CARE* | Online – 4 February 2019 – ‘‘**Small small interventions, big big roles**: A qualitative study of patient, caregiver and healthcare worker experiences of a palliative care programme in Kerala, India.’ Doctors, nurses and volunteers have interdependent roles in providing palliative care to patients, including mentorship, training, patient care and advocating for patient needs. Volunteers also consider themselves to be mediators between families and the programme. Caregivers were mainly female and were caring for relatives. They have physically demanding, psychologically stressful and socially restrictive experiences of caregiving. They feel that the programme facilitated their role as caregivers by giving them training and support. **Full text:** <http://bit.ly/2RFEKOX>

Noted in Media Watch 25 June 2018 (#569, p.15):

- *THE PERMANENTE JOURNAL*, 2018;22(2):17-151. ‘**Home-based palliative care program relieves chronic pain in Kerala, India: Success realized through patient, family narratives.**’ The state of Kerala is home to Pallium India, one of the most sophisticated palliative care (PC) programs in the country. This private organization in Trivandrum provides palliative and hospice care to under-resourced populations and emphasizes holistic pain treatment. The current project features the pain stories of six patients who received treatment from Pallium India. Patient pain narratives illustrate the substantial impact of Pallium India’s home visit program and the role of total pain assessment in delivering high-quality PC. **Full text:** <http://bit.ly/36CiGwT>



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

Compassion in pediatric healthcare: A scoping review

JOURNAL OF PEDIATRIC NURSING, 2020;51(2):57-66. Compassion has been described as a central construct or essential feature of quality healthcare and is as important to patients' and families' overall healthcare experience as the health interventions and treatments they receive. However, there is little shared understanding of what constitutes compassion, how it is delivered within a pediatric setting, and pediatric patients' and families perspectives and preferences for receiving it. Findings of this review revealed several factors are associated with compassion in pediatric healthcare, including continuity of care, communication, and coordination of care. Most notably, identified studies treated compassion in a subsidiary fashion, and this review revealed no studies that provided a patient-informed evidence-based definition of compassion in the pediatric healthcare setting. Future research is required to generate a comprehensive and accurate understanding of the terms "compassion" and "compassionate care" when used in the context of pediatric healthcare. **Abstract:** <http://bit.ly/35BDDqE>

"I keep it together at work but fall apart at home": The experience of Israeli homeroom teachers coping with the death of a student in their class

OMEGA – JOURNAL OF DEATH & DYING | Online – 9 January 2020 – This study examines the experiences of 16 Israeli high school homeroom teachers coping with the death of a student from their class. The authors used in-depth, semi-structured, face-to-face interviews. Analysis of the findings revealed three key themes: 1) After their initial sense of shock and pain upon learning of the death of one of their students, the homeroom teachers were immediately asked to convey the bad news to their class; 2) The teachers experienced profound grief, had difficulty dealing with the student's absence, and invested resources in preserving the student's memory through various activities; and, 3) The teachers claimed that the experience affected their personal lives and stated that memories of

it continued to surface long afterwards. Some found it difficult to function and even chose to leave the profession. The discussion raises the need for early assessment and planning in schools to address loss-related issues and provide support for teachers. **Abstract (w. list of references):** <http://bit.ly/35LSL4u>

CANADIAN  Portail CANADIEN EN SOINS
Virtual Hospice **palliatifs**

Supporting Grieving or Bereaved Children
<http://bit.ly/2sQ2bLy>

Bridging the divide between law and palliative medicine

PALLIATIVE MEDICINE | Online – 8 January 2020 – The way law and human rights shape palliative care (PC) must be accounted for and scrutinised. Whether explicitly recognised or not, human rights have always had a place at the heart of PC as it is a practice which aims to respect, protect, and promote the inherent dignity of the individual. Through the legal, political and moral weight afforded to human rights they can be influential in shaping discourse and defining key priorities. This is the potential offered by closer and deeper engagement with human rights. There are challenges in applying a human rights-based approach, but it offers the possibility of greater control and an opportunity to use law as a tool for change. **Full text:** <http://bit.ly/2sfaT9r>

Choice depends on options: A public health framework incorporating the social determinants of dying to create options at end of life

PROGRESS IN PALLIATIVE CARE | Online – 5 January 2020 – Our choice for care at the end of our lives is constrained by many factors, including the options available to us, our capacity to choose and the social structures that constrain our options and therefore our choices. Working with the interaction between personal agency and social constraints is a core public health activity. An intentional public health

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approach to palliative and end-of-life (EoL) care can elucidate the direct relationship between our social circumstances and the quality of our EoL and uncover the implications of structural inequity for EoL choice. The approach reorients systems and settings to achieve accessible and equitable palliative and EoL care for all, and identifies contributions that all jurisdictions, settings, organisations, sectors and communities can make to improving EoL care outcomes. Frameworks that support this shift in practice and policy are however in their infancy. Implementation frameworks that can structure and guide “how” to translate public health palliative care (PC) concepts into sustainable practice are needed. The authors of this article report on an evidence-based Australian public health PC framework designed to achieve this.

Abstract: <http://bit.ly/2ZRMycw>

Community participation in palliative care: Reflections from the ground

PROGRESS IN PALLIATIVE CARE | Online – 5 January 2020 – Community participation is a frequently mentioned theme in palliative care projects. Yet most of the projects claiming to be community-led have only minimal participation from the community, usually in the form of resource mobilization. Achieving higher levels of participation, the process of involving community collectives as partners in running, and later taking responsibility to sustain and own the program, is more complex and more difficult to achieve. Common barriers include lack of the mandatory preparatory work to understand the social and political dynamics of the community, facilitators’ values and agenda assuming the dominant role in the project, unwillingness on the part of facilitators to give up control and problems with the “political process” that should go with capacity building. Another issue is that community mobilization, being a dynamic cascading process, does not yield to conventional methods of evaluation. **Abstract:** <http://bit.ly/2T0em6D>

The role of palliative care in reducing symptoms and improving quality of life for patients with idiopathic pulmonary fibrosis: A review

PULMONARY THERAPY | Online – 4 January 2020 – Despite the increasing prevalence of idiopathic pulmonary fibrosis and its growing recognition among providers, there remains a significant lag time between initial diagnosis and multidisciplinary evaluation. This has contributed to delays in management, as well as patient and caregiver confusion and frustration over the natural disease course. Disease progression is associated with functional decline and varying symptom burden, ultimately affecting quality of life of both the patient and their caregiver(s). While beneficial in other patient populations, the benefits of palliative care have not been replicated in this patient population. It may be misconstrued as hospice and end-of-life care, resulting in delayed evaluation often far too late in a patient’s disease course to have meaningful symptomatic benefit. **Full text:** <http://bit.ly/2N0lOuS>

Noted in Media Watch 6 August 2018 (#575, p.13):

- *PALLIATIVE MEDICINE* | Online – 30 July 2018 – ‘**Early integrated palliative approach for idiopathic pulmonary fibrosis: A narrative study of bereaved caregivers’ experiences.**’ Idiopathic pulmonary fibrosis has an uncertain and rapid trajectory after diagnosis. Palliative care is rarely utilized, although both patients and caregivers experience a distressingly high symptom burden. Most patients die in hospital. Five major themes were identified: 1) Having a terminal disease; 2) Planning goals and wishes for care; 3) Living life and creating memories; 4) Feeling strain and responsibility; and, 5) Nearing the end. Caregivers interviewed had little understanding of prognosis prior to advance care planning conversations... **Abstract:** <http://bit.ly/2T1az90>

Rehabilitation Oncology: Special issue on hospice and palliative care

REHABILITATION ONCOLOGY, 2020;38(1). This issue focuses specifically on palliative and hospice care. The editors curated an interdisciplinary collection of pieces linked by the common thread of offering the rehabilitation professional with another perspective necessary in caring for those with life-limiting illness. While physical therapists are frequently comfortable in their role of providing rehabilitation services, hospice and palliative care (PC) is no less an important domain for the practice of rehabilitation. Provision

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of such rehabilitative services at the end of life (EoL) provides a higher quality of life for a longer period, and often results in greater sense of well-being. This sense of well-being is important, too, in all individuals, and one perspective piece provides an understanding of the disparities within EoL care, and provides evidence-based strategies for best practice. Adding to the complexities of the EoL experience is the spiritual impact of illness on the person, one author provides an important lesson in the role physical therapists can take to help heal the non-visible wounds that life-limiting illnesses effect on an individual. Each article in this issue provides the reader with valuable insights and information when working with individuals in the hospice and PC setting. **Journal contents page:** <http://bit.ly/2FmvUC5>

Noted in Media Watch 6 January 2020 (#647, p.4):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 30 December 2019 – ‘**Rehabilitation in palliative care: A qualitative study of team professionals.**’ The concept of rehabilitative palliative care (PC) has been advocated to help patients preserve function and independence, through greater patient enablement and self-management. Such an approach requires engagement from all members of the PC team. The objective of this research was to explore hospice-based PC professionals’ understanding and perceptions of rehabilitation. Overall, participants in this study clearly articulated the underlying values and benefits of rehabilitative PC. Emphasis was placed on ensuring that rehabilitation was appropriately tailored to each individual patient. **Abstract:** <http://bit.ly/2Qb5BF8>

Noted in Media Watch (#633, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 September 2019 – ‘**Top ten tips palliative care clinicians should know about physical medicine and rehabilitation.**’ This article, written by a team of physical medicine and rehabilitation (PM&R) and palliative care (PC) specialists, aims to help the PC team ... expand their toolkit for treating musculoskeletal and neurological symptoms, improve prognostication for patients with brain and spinal cord injuries, and decide when patients may benefit from PM&R consultation and support. There is significant overlap between the populations treated by PM&R and PC. Better integration between these specialties will help patients to maintain independence as well as advance excellent patient-centered care. **Abstract:** <http://bit.ly/2lxH54o>

Publishing Matters

Publishing habits and perceptions of open access publishing and public access amongst clinical and research fellows

JOURNAL OF THE MEDICAL LIBRARY ASSOCIATION, 2020; 108(1):47-58. Open access (OA) publishing rates have risen dramatically in the biomedical sciences in the past decade. However, few studies have focused on the publishing activities and attitudes of early career researchers. The aim of this study was to examine current publishing activities of clinical and research fellows and their perceptions of OA publishing and public access. The total percentage of fellows’ publications that were freely available OA was 28.6%, with a relatively flat rate between 2013 and 2018. Publications with fellows as first authors were significantly more likely to be OA. Fellows cited high article processing charges (APCs) and perceived lack of journal quality or prestige as barriers to OA publishing. Fellows generally expressed support for the National Institutes of Health (NIH) public access policy. While the fellows in this study acknowledged the potential of OA to aid in research dissemination, they also expressed hesitation to publish OA related to confusion surrounding legitimate OA and predatory publications and frustration with APCs. **Abstract (w. list of references):** <http://bit.ly/2Tdw4Ux>



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[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

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Barry R. Ashpole, Ontario CANADA

e-mail: barryashpole@bell.net