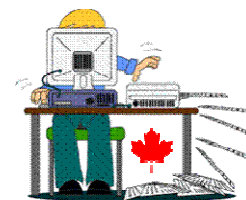


## Media Watch...

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.

23 December 2019 Edition | Issue #645



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Compiled & Annotated by Barry R. Ashpole

**Despite strongly favouring the concept, both specialists and primary providers lack resources to deliver early palliative care (PC); its provision may be facilitated by team-based care with appropriate support. Opinions differ regarding the value of renaming PC.**

'Readiness for delivering early palliative care: A survey of primary care and specialised physicians' (p.9), in *Palliative Medicine*.

## Canada

### Medical assistance in dying

#### Canadian palliative society supporting Delta Hospice

BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 18 December 2019 – The public and many healthcare providers have had a longstanding fear that hospice [and] palliative care (PC) hastens peoples' deaths, something that will be made worse if facilities are forced to provide medically-assisted deaths. That's what the Canadian Society of Palliative Care Physicians (CSPCP) is saying in a letter to the province's Health Minister Adrian Dix in support of the Delta Hospice Society, which is *not* providing medical assistance in dying (MAiD). [Delta Hospice] Society president Angelina Ireland provided the *Optimist* with a copy of the letter expressing concern that PC centres ... such as hospices, would be mandated to provide MAiD on site. "While we appreciate the requirement for MAiD to be available, requiring it to be provided in hospices and PC units poses risk for potential harm," wrote CSPCP president Dr. Leonie Herx. Herx ... provided [the *Optimist* with] a CSPCP

submission to a federal special joint committee on physician-assisted death...,<sup>1</sup> as well as a recent joint statement with the Canadian Hospice Palliative Care Association,<sup>2</sup> which notes that hospice and PC and MAiD substantially differ ... in philosophy, intent and approach. Noting one of the biggest potential harms is to those who do not choose MAiD, which is more than 98% of those dying, Herx said it has led to late referrals and people choosing to not be referred to PC services that could have benefited them. <http://bit.ly/2r8VuH3>

### Specialist Publications

'Quality of care with telemedicine for medical assistance in dying eligibility assessments: A mixed-methods study' (p.13), in *CMAJ Open*.

Cont.

1. 'Presentation to Special Joint Committee on Physician-Assisted Death,' Canadian Society of Palliative Care Physicians, July 2016. **Download/view at:** <http://bit.ly/38TNbjj>
2. 'Joint Statement Regarding Palliative Care and Medical Assistance in Dying,' Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, December 2019. [Noted in 2 December 2019 issue of Media Watch (#642, p.1). **Download/view at:** <http://bit.ly/33mmlad>

## U.S.A.

### The movement to bring death closer

*THE NEW YORK TIMES* | Online – 19 December 2019 – In the U.S., we have come to see death as an emergency. We call the doctors, the nurses, the police, the emergency workers, the funeral staff to take over for us. They hurry corpses from hospital rooms or bedrooms into designated, chilled death spaces. They dig and fill the graves for us and drive our loved ones, alone, to the crematories. They turn on the furnace, lift the bodies, close the door. There may be no other rite of passage around which we have become more passive. We carefully vet the doctors or midwives who will deliver our babies. We pore over options for wedding venues and officiants. But often we don't plan for death. So when it arrives, we take what's easily available. <https://nyti.ms/2MevAcq>

#### Specialist Publications

**'Their last breath: Death and dying in a Hmong American community'** (p.6), in *Journal of Hospice & Palliative Nursing*.

**'Medical aid in dying, hastened death, and suicide: A qualitative study of hospice professionals' experiences from Washington State'** (p.13), in *Journal of Pain & Symptom Management*.

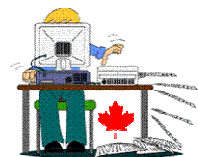
### Breakdown in Monroe prison left man to die of cancer

WASHINGTON STATE | *The Daily Herald* (Snohomish) – 17 December 2019 – Seven months after a nurse found a lump in his chest, an inmate at the Monroe prison wrote a note to the only people who could help him. "I do not have long to live according to an outside specialist who is the fourth leading cancer doctor in the world," the man wrote in fall 2018. "He told me I need to start chemo aggressively right away or would not live nine months. This was 2 months ago. What is taking so long?" The man died in June 2019. For more than a year, he'd received no real treatment for his cancer, according to findings released ... by the state Office of the Corrections Ombudsman. The man was due for release six months after the date of his eventual death, with time off for good behavior. His passing has led to reforms in how medical issues are handled and documented at the Monroe Correctional Complex. <http://bit.ly/2tol2AF>

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

#### 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>



## Mapping community palliative care: A snapshot

CENTER TO ADVANCE PALLIATIVE CARE | Online – 16 December 2019 – More than 87% of all hospitalized Americans are admitted to hospitals with palliative care (PC) teams. More recently, healthcare organizations are providing PC in the community to meet the needs of patients with serious illness who are neither hospitalized nor ready or eligible for hospice. Community settings include office practices, medical clinics, long-term care facilities, and patients' homes. Several studies show that community PC reduces hospital and emergency department visits, lowers acute care costs, and improves care continuity, quality of life, and survival outcomes. This foundational report provides the first scan of community PC programs in the U.S. Although likely an underrepresentation of the true number and not nationally representative, the Center's data provide important insights as to what types of organizations are developing community PC capacity, what settings of care are being served, and the ages of patients being cared for. Future work is needed to better identify community PC programs and to characterize care models, populations served, clinical capacity, and adherence to quality guidelines. **Download/view at:** <http://bit.ly/2tswrzB>



## International

### Lancashire fire service's pledge to help employees who become terminally ill

U.K. (England) | *Lancashire Telegraph* – 18 December 2019 – Lancashire Fire & Rescue Service is the latest employer to sign up to the Dying to Work Voluntary Charter. The charter is part of the Trade Union Congress' wider Dying to Work campaign which is seeking greater security for terminally ill workers so they cannot be dismissed as a result of their condition. <http://bit.ly/38OpXuZ>

**N.B.** Selected articles on the Dying to Work campaign noted in 11 December 2017 issue of Media Watch (#542, p.5). Campaign website: <http://bit.ly/2PyvWww>

### Hospice to close for 9 weeks due to lack of doctors

U.K. (England) | *Echo Newspapers* – 17 December 2019 – Fair Havens Hospice in Chalkwell Avenue, Westcliff, which opened in 1982, has announced it will close to patients for “a minimum of nine weeks” after its palliative care consultant retired amid a national shortage of experts in the field. Staff will be redeployed to care for people in their homes – and at its day centre in Westcliff. <http://bit.ly/2YZctbt>

**N.B.** Selected articles on the shortage of doctors and nurses in the U.K., and the funding of hospices, noted in 25 November 2019 issue of Media Watch (#641, p.5).

### In France, dying at home can mean a long wait for a doctor

FRANCE | *The New York Times* – 16 December 2019 – It is illegal in France to move a body without a death certificate, which only a doctor can sign. But a doctor can be hard to find. Mayors, councilors, police officers, firefighters and other officials find themselves scrambling to help families find a willing doctor capable of coming to certify a death, though neither the government nor medical associations keep data that

### Specialist Publications

**'Sustainable access to appropriate opioids for palliative care patients in Australia. Preventing the need for crisis management'** (p.7), in *Journal of Pain & Palliative Care Pharmacotherapy*.

**'Palliative care guidelines for the management of HIV-infected people in South Africa'** (p.11), in *South African Journal of HIV Medicine*.

**'After the Italian Constitutional Court's ruling on the absence of criminal liability for assisted suicide: The role of ethics committees and clinical ethics'** (p.12), in *Annali*.

Cont.

would indicate precisely how widespread these delays have become. Exasperated, one town issued a bylaw forbidding its residents to die at home. The mayor of Douai took a more conventional approach, recently writing to the health minister that he had faced four such cases in the past year and that desperate residents regularly called him for help in finding a doctor to certify a relative's death. Nurses, coroners, pathologists and other officials can certify deaths in countries like the U.S. But in France, where a quarter of the population dies at home, the role is reserved for medical doctors, who must visit the deceased's home, verify that the death was natural and note its cause. It is a system that functioned well when France had a surfeit of general practitioners, many of whom made house calls. Today, while an acute shortage of doctors in some areas has created what the French called "medical deserts," the requirements for obtaining death certificates have essentially remained the same. <https://nyti.ms/2rR9Goy>

## Specialist Publications

### **Prognostic awareness, disease and palliative understanding among caregivers of patients with dementia**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 19 December 2019 – Persons with dementia (PwD) often have significant cognitive deficits and functional limitations, requiring substantial caregiver assistance. Given the high symptom burden and terminal nature of dementia, good prognostic awareness and integration of palliative care (PC) is needed. This cross-sectional study focused on prognostic awareness, disease, and PC understanding among caregivers of PwD and to assess for improvements in routine care. 154 of caregivers completed a survey.... Prognostic discussions between caregivers of PwD and the PwD's physicians may be occurring more often; however, a

high percentage of caregivers report a poor understanding about the terminal nature of dementia and the role of PC. **Abstract (w. list of references):** <http://bit.ly/2EBPbPh>

#### Publishing Matters

'Predatory publishing, hijacking of legitimate journals and impersonation of researchers via special issue announcements: A warning for editors and authors about a new scam' (p.13), in *Australasian Physical & Engineering Sciences in Medicine*.

Noted in Media Watch 16 December 2019 (#644, p.8):

- *BMJ OPEN* | Online – 11 December 2019 – '**Social networks, social capital and end-of-life care for people with dementia: A realist review.**' Comparatively few interventions and/or end-of-life policies are designed to address the complexities highlighted by the multiple contexts and mechanisms identified in this review. As a public health approach to palliative care gathers pace, it is important that "community" or "social capital" is not viewed as a universal solution to the mounting public health crisis. This study highlights the need to take a more dispassionate approach, studying its potential in all its complexity in order to further understand what works for whom and in what circumstances. **Full text:** <http://bit.ly/2PBr8VX>

### **A conceptual model of barriers and facilitators to primary clinical teams requesting pediatric palliative care consultation based upon a narrative review**

*BMC PALLIATIVE CARE* | Online – 21 December 2019 – Despite evidence that referral to pediatric palliative care (PC) reduces suffering and improves quality-of-life for patients and families, many clinicians delay referral until the end of life. The purpose of this article is to provide a conceptual model for why clinical teams delay discussing PC with parents. Building on a prior model of parent regoaling and relevant research literature, the authors argue for a conceptual model of the challenges and facilitators a clinical team might face in shifting from a restorative-focused treatment plan to a plan that includes palliative aspects, resulting in a sub-specialty PC referral. **Full text:** <http://bit.ly/2tEhURn>



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## Advance healthcare directives: Binding or informational value?

*CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS* | Online – 20 December 2019 – Advance directives (ADs) entail a refusal expressed by a still-healthy patient. Three consequences stem from that fact: 1) Advance refusal is unspecific, since it is impossible to predict what the patient's conditions and the risk-benefit ratio may be in the foreseeable future; 2) Those decisions cannot be as well informed as those formulated while the disease is in progress; 3) While both current consent and refusal can be revoked as the disease unfolds, until the treatment starts out, ADs become effective when the patient becomes incapable or unconscious; such decisions can therefore not be revoked at any stage of the disease. Therefore, ADs are binding for doctors only at the stage of advance treatment planning, i.e., only if they refer to an illness already in progress. **Abstract (w. list of references):** <http://bit.ly/2EEpkqg>

**N.B.** See 'Commentary: On the moral bindingness of advance directives,' *Cambridge Quarterly of Healthcare Ethics*, published online 20 December 2019. **First page view:** <http://bit.ly/2rYdbK2>

### Related:

- *DEATH STUDIES* | Online – 20 December 2019 – '**Developing and using a structured, conversation-based intervention for clarifying values and preferences for end-of-life in the advance care planning-naïve Swedish context...**' Sweden has no systematic advance care planning (ACP), nor legal recognition of end-of-life (EoL) proxies. The authors describe their experiences and reflections from a participatory action research process, aiming at developing and initially using a conversation-based, structured ACP approach among community-dwelling, older adults in Sweden. DöBra cards were concluded to be a viable tool for stimulating person-centered conversations on preferences for future EoL care. **Full text:** <http://bit.ly/36UZDxt>
- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 18 December 2019 – '**Advance care planning: Social isolation matters.**' Social isolation is a risk factor for poor health that influences the well-being of older adults. Approximately 23% of the 2,015 older adults who participated in this study, selected from a representative sample of community-dwelling Medicare beneficiaries, and who experienced social isolation, were less likely to engage in advance care planning (ACP) than those who were not socially isolated. Clinicians should identify older adults who are at risk for or experience social isolation as they may benefit from targeted ACP efforts. **Abstract (w. link to supporting information):** <http://bit.ly/2s41XDz>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 December 2019 – '**Factors which influence hospital doctors' advance care plan adherence.**' Simultaneously, countries such as Australia, Canada, the U.S., New Zealand, the U.K. and Germany have encouraged consumer-directed care and advance care plan (ACP) completion, giving patients a voice despite incapacity. Adhering to ACPs relies on the decision-making of treating doctors, making hospital doctors key partners, and their perspectives on ACP adherence critical. Current literature suggests doctors' hold largely positive attitudes towards ACPs that provide useful patient information that enables doctors to make appropriate treatment decisions. **Abstract (w. link to references):** <http://bit.ly/2RUmrJq>

## How are older people's care preferences documented towards the end of life?

*COLLEGIAN* | Online – 6 December 2019 – Fifty records were audited [by the authors], including 28 hospital, 12 residential aged care facilities, and 10 community palliative care records with overall 297 documented care preferences. 30% of preferences were recorded on institution-specific forms at admission which focussed on patients' medical/healthcare needs and less on personal/lifestyle preferences. Documentation mainly included clinical care preferences (35%), resuscitation plans (28%), and place of care (20%). Preferred place of death was not documented in 70% of cases. Increased documentation occurred closer to death with 63% of preferences recorded in the last week of life. The low rates of recorded preferences, especially non-medical choices like preferred place of death, may indicate low rates of preference discussions and/or poor documentation of these conversations. The increase in documentation closer to death may be explained by increased care needs and higher rates of care place transitions towards the end of life. **Full text:** <http://bit.ly/2tkTJr6>





## **Palliative care and heart failure: Can implementation science help where the evidence alone has failed?**

*EUROPEAN JOURNAL OF CARDIOVASCULAR NURSING* | Online – 16 December 2019 – Recent decades have witnessed a continuous stream of healthcare innovations, from diagnostic tools to therapeutic approaches, all promising a better quality of life (QoL) for patients. However, the promised benefits are rarely experienced by patients, due to lack of attention on how to implement novel interventions in practice. Put quite simply, too much focus is put on trying to evidence effectiveness through a linear cause and effect approach, which fails to ignore the messy, non-linear world of real-life practice. What are we left with? Frustrated researchers, disillusioned clinicians and patients with continuing unmet needs. With the alarming reality that 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) – when patients have refractory symptoms despite optimal medical or device therapy, or have limited options for escalation of therapy – a palliative care (PC) approach integrated with conventional/active HF management has strong evidence for improved outcomes for patients in terms of QoL, symptom burden, caregiver outcomes and reductions in health service costs. However, patients with HF across Europe are still marginalised when it comes to receiving PC. **Full text:** <http://bit.ly/2S6NRfz>

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

## **Human relationships in patients' end-of-life: A qualitative study in a hospice ward**

*INTERNAL & EMERGENCY MEDICINE* | Online – 17 December 2019 – A descriptive qualitative study was conducted in the hospice department at ARNAS Civico in Palermo, Italy. From a qualitative research point of view, a significant sample of ten dying patients was interviewed. Five themes emerged: 1) Experiencing hospice; 2) Hospice staff; 3) Family role; 4) Coping with the disease; and, 5) death. Human relationships seem to represent a fundamental key in patients' end-of-life, especially in their family fondness. Predictably, terminally ill patients seem to fear pain and incoming death. Even though patients had everything they needed in the hospice, their main thoughts were always focused on human relationships. **Abstract (w. list of references):** <http://bit.ly/34F0fWA>

## **Their last breath: Death and dying in a Hmong American community**

*JOURNAL OF HOSPICE & PALLIATIVE NURSING* | Online – 3 December 2019 – Hmong Americans have typically been unwilling to use biomedical palliative care (PC) for end-of-life (EoL) needs. This has resulted in confusion and frustration for Hmong patients, families, and nurses. Hmong's EoL care choices for family members usually involve in-home caregiving provided by the family using a combination of biomedicine and traditional healing methods. Healthcare decisions are made for the patient by the family and community in this familistic culture. A qualitative approach was used to explore the beliefs that ultimately determine EoL care goals and strategies for Hmong patients. Several themes affecting care choices were identified, including cultural legacies of the responsibility of EoL caregiving by the family, the desire for family privacy in caregiving, and the role of community in the care for the dying, as well as completion of the rituals that ensure the soul of the deceased reaches the afterlife. Suggestions for improving communication between Hmong and biomedical providers include providing information about EoL care beliefs and strategies to biomedical care providers and providing information to Hmong patients and families about hospice and PC options and services to support family care. **Abstract:** <http://bit.ly/38EgID3>

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**Related:**

- *JOURNAL OF TRANSCULTURAL NURSING*, 2019;30(6):576-586. **'Nurses' perceptions of basic palliative care in the Hmong population.'** Assisting tradition, understanding culture, and managing language barriers were identified as themes unique to providing basic palliative care (PC) to Hmong patients. Nurses experienced uncertainty and inadequacy of resources when caring for patients from a Hmong background. They also recognized the strong family ties in this specific population and the importance of supporting tradition while in the hospital. Utilizing Wood & Schwass' framework of cultural safety could guide nurses providing basic PC to Hmong patients and other culturally diverse patients. **Abstract (w. list of references):** <http://bit.ly/2M1lgTE>

Noted in Media Watch 26 November 2018 (#591, p.14):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 20 November 2018 – **'Walking in two worlds: Hmong end-of-life beliefs and rituals.'** Many Hmong elders continue to honor healthcare and end-of-life (EoL) beliefs and rituals that they practiced in their home country. With little knowledge by the general public and healthcare systems about these beliefs and rituals, healthcare professionals may struggle to provide the Hmong community with culturally-sensitive care. Both Animist and Christian interviewees believed family should provide care at EoL. Animist Hmong elders reported the importance of Shamanistic rituals such as soul calling or spiritual offering while Christian Hmong elders believed in the power of prayers. **Abstract:** <http://bit.ly/2YMWvB6>

**N.B.** According to a 2016 census, there are more than 250,000 Hmong Americans living in the U.S.

**Sustainable access to appropriate opioids for palliative care patients in Australia. Preventing the need for crisis management**

*JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 11 December 2019 – The author considers the recent history and current issues of the “opioid crisis” providing recommendations to which regulatory and peak bodies can work with the Australian government, ensuring consistent adherence to WHO guidelines maintaining access to evidence based opioid management for palliative care (PC) patients whilst actively avoiding unintended suffering restricted access can cause. The recommendations are: 1) Review of the PC schedule of the Pharmaceutical Benefit Scheme; 2) Support of prescribers with current evidence, clinical practice guidelines and regulatory frameworks; 3) National opioid prescribing policies promoting linkages between PC and pain and addiction specialists; 4) National real time monitoring of all opioid prescriptions; 5) PC involvement in all opioids stewardship programs in acute services; 6) Reform Medical Benefits Schedule to improve access for primary and other speciality practitioners to provide PC services; 7) Compulsory PC education in undergraduate medical, nursing and allied health tertiary courses; and, 8) Adequate, consistent stock of evidence based opioids for PC in community pharmacies and residential aged care facilities. These recommendations provide the regulatory guidance required to ensure persons with life-limiting illness have continued access to safe and effective medication that can relieve suffering. **Abstract:** <http://bit.ly/2EIUNxg>



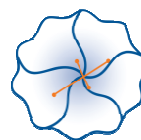
Noted in Media Watch 10 June 2019 (#617, p.12):

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

**N.B.** Selected articles on opioid prescribing in PC noted in 2 December and 25 November 2019 issues of Media Watch (#642, p.6 and #641, pp.10-11, respectively).

## Analysis of the results of a palliative care quality program for the last days of life. Ten years of experience

*MEDICINA*, 2019;79(6):468-476. The Pallium Multidisciplinary Assistance Program (PAMPA ©) was implemented based on standards of the International Collaborative for Best Care for the Dying Person in 4 phases: induction, implementation, dissemination and sustainability, in five health centres in Argentina, between 2008 and 2018. A total of 1,237 adult patients in the last days of life were included and cared for by palliative care teams trained in PAMPA©. An audit was conducted before and after the implementation of the Program... The median range of follow up into five centres from the beginning of the pathway until death varied from 16 to 178 hours. Care goals were compared: symptom control, communication, multi-dimensional needs, hydration and nutrition, documentation of interventions and post-mortem care. The overall analysis showed an improvement in the number of records. The goal of communication on care plan to the patient showed no difference. Continuous training, support and permanent teams supervision were carried out and perceptions and impact of the implementation were registered. The main emerging items of the qualitative analysis were: attitudes towards the program, fundamental contributions, strengths, weaknesses and subjective definition of the program, recognition of institutional cultural singularities and its influence on care. PAMPA© demonstrated its feasibility as a model of end-of-life care for patients and families, based on international quality standards. **Abstract (via PubMed):** <http://bit.ly/2Q1ARoM>



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LATINOAMÉRICA  
MEDICINA PALIATIVA**

**N.B.** Spanish language article.

## Relational ethics in palliative care research: Including a person-centred approach

*PALLIATIVE CARE & SOCIAL PRACTICE* | Online – 19 December 2019 – The authors demonstrate how person-centredness situated in practice is needed in addition to the traditional procedural ethical approach to ensure ethical practice in many palliative care (PC) research contexts. Rather than being a scrutinising process by an external research ethics committee prior to the study starting, they reveal how ethical research practice also needs to be contextual and located in practice. The four principles of person-centred research presented in this article can be the starting point in developing a research culture in PC which has person-centeredness at its core. Supplemented with a process consent model, this can make explicit research proposals on how the principles will guide ethical practice. This is a process that will expose the real challenges inherent in PC research and raise awareness of the importance of paying attention to ethical relationships throughout the whole research process not only prior to research. **Full text:** <http://bit.ly/2s6tFQc>

### Related:

- *HEALTH RESEARCH POLICY & SYSTEMS* | Online – 16 December 2019 – **‘Palliative Care Evidence Review Service (PaCERS): A knowledge transfer partnership.’** The importance of linking evidence into practice and policy is recognised as a key pillar of a prudent approach to healthcare; it is of importance to healthcare professionals and decision-makers across the world in every speciality. However, rapid access to evidence to support service redesign, or to change practice at pace, is challenging. This is particularly so in smaller specialties such as palliative care, where pressured multidisciplinary clinicians lack time and skill sets to locate and appraise the literature relevant to a particular area. **Full text:** <http://bit.ly/35Jsll3>



### Media Watch: Access Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.14.



## Economic evaluations of palliative care models: A systematic review

*PALLIATIVE MEDICINE* | Online – 19 December 2019 – A systematic search of nine medical and economic databases was conducted and extended with reference scanning and gray literature. The authors identified 12,632 articles and 5 were included. They included two modeling studies from the U.S. and England, and three economic evaluations from England, Australia, and Italy. Two studies compared home-based palliative care (PC) models to usual care, and one compared home-based PC to no care. Effectiveness outcomes included hospital readmission prevented, days at home, and PC symptom severity. All studies concluded that PC was cost-effective compared to usual care. The methodological quality was good overall, but three out of five studies were based on small sample sizes. Applicability and generalizability of evidence is uncertain due to small sample sizes, short duration, and limited modeling of costs and effects. Further economic evaluations with larger sample sizes are needed, inclusive of the diversity and complexity of PC populations and using patient-centered outcomes. **Abstract (w. list of references):** <http://bit.ly/2Z7dxdm>



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## Understanding what works, why and in what circumstances in hospice at home services for end-of-life care: Applying a realist logic of analysis to a systematically searched literature review

*PALLIATIVE MEDICINE* | Online – 18 December 2019 – Forty-nine papers were reviewed, of which 34 contributed evidence to at least one of the eight theory areas: 1) Marketing and referral; 2) Sustainable funding model; 3) Service responsiveness and availability; 4) Criteria for service admission; 5) Knowledge and skills of care providers; 6) Integration and coordination; 7) Anticipatory care; and 8) Support directed at carers. This literature review showed how it was possible to develop a coherent framework and test it against 34 published papers and abstracts. Central to this review was theory building, and as further evidence emerges, programme theories can be refined and tested against any new empirical evidence. **Abstract (w. list of references):** <http://bit.ly/2Sckloz>

### Related:

- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 19 December 2019 – ‘**Support for family caregivers: A scoping review of family physician’s perspectives on their role in supporting family caregivers.**’ Undoubtedly, there is increased awareness that caregivers need support. Primary healthcare teams are well positioned to connect caregivers to both primary care practices and their communities, but the policy and funding required to drive change has been limited. Physicians’ perspectives about caregiver interactions are needed to inform health and community service planning. Future work to address these limitations is needed to support caregivers throughout their care trajectory. **Full text:** <http://bit.ly/35K7IF4>
- *JOURNAL OF PALLIATIVE CARE* | Online – 15 December 2019 – ‘**An environmental scan of caregiver support resources provided by hospice organizations.**’ Informal caregiver support programs offered by hospice organizations support the health and wellbeing of clients and caregivers. However, an understanding of the best practices for informal caregiver support programs currently undertaken across Canada remains unknown, particularly across the province of British Columbia. While no one-size-fits-all caregiver support program emerged as a gold standard across all hospice organizations, nearly two thirds [of hospices participating in this descriptive study] offered one or more informal caregiver support programs. **Abstract (w. list of references):** <http://bit.ly/34whXvy>

## Readiness for delivering early palliative care: A survey of primary care and specialised physicians

*PALLIATIVE MEDICINE* | Online – 18 December 2019 – Evidence supporting early palliative care (PC) is based on trials of specialised PC, but a more sustainable model might involve mainly primary providers. The aim of this study was to compare the characteristics of physicians providing primary and specialised PC, their attitudes towards early PC and their perception of having sufficient resources for its provision. Of the participants, 257 (48.4%) provided specialised and 274 (51.6%) primary care. Specialists were more likely to have PC training (71.8% vs. 35.2%), work in urban areas (94.1% vs. 75.6%), academic centres

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(47.8% vs. 26.0%) and on teams (82.4% vs. 16.8%), and to provide mainly cancer care (84.4% vs. 65.1%). Despite strongly favouring early PC, only half in each group agreed they had resources to deliver it; agreement was stronger among family physicians, those working on teams and those with greater availability of community and psychosocial support. Primary providers were more likely to agree that renaming the specialty “supportive care” would increase patient comfort with early PC referral (47.4% vs. 35.5%). Despite strongly favouring the concept, both specialists and primary providers lack resources to deliver early PC; its provision may be facilitated by team-based care with appropriate support. Opinions differ regarding the value of renaming PC. **Abstract (w. list of references):** <http://bit.ly/2Pzt82j>

Noted in Media Watch 19 August 2019 (#627, p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 16 August 2019 – ‘**Using the term “palliative care”**: International survey of how palliative care researchers and academics perceive the term “palliative care.”’ The term “palliative care” (PC) has often been found to have a negative connotation leading some to suggest rebranding and some services to change their name. Perceptions of the PC community about the term remain largely unexplored. This is a cross-sectional survey of attendees to the 10th World Research Congress of the European Association for Palliative Care. For 40% [of survey respondents], the term hindered the positioning of PC, 28% worried about using the term, and 55% did not discuss these difficulties. **Abstract:** <http://bit.ly/2P8K01l>

Noted in Media Watch 4 March 2019 (#604, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 28 February 2019 – ‘**Changing perceptions is more important than changing names.**’ Nearly 30 years after the WHO first defined “palliative care” (PC) we are no closer to agreeing what the term means. PC has driven major improvements in the care of people with life-limiting illnesses and fostered more open public discourse about death and dying. National and international policies advocate better access to PC for everyone who needs it. *The Lancet* Commission goes further, describing it as a basic human right in the face of unrelieved suffering affecting millions worldwide.<sup>1</sup> Yet, stigmatisation of the term among patients, professionals, and the public continues to counter positive messages about its benefits. **Introductory paragraph:** <http://bit.ly/2NzLBsA>

1. ‘Alleviating the access abyss in palliative care and pain relief: An imperative of universal health coverage,’ *The Lancet*, October 2017. [Noted in 16 October 2017 issue of Media Watch (#534, p.14)] **Full text:** <http://bit.ly/2Ww8Cku>

**N.B.** Selected articles on defining palliative and end-of-life care noted in this issue of Media Watch.

## Compassionate cities: Global significance and meaning for palliative care

*PROGRESS IN PALLIATIVE CARE* | Online – 18 December 2019 – Compassionate cities programs are civic efforts to contribute to the work of palliative care (PC) by providing a variety of supports – educational, interpersonal, policy-oriented – for the end-of-life (EoL) care needs for people from all walks of life in the wider society. These programs are public health initiatives that trace their history to the World Health Organization Healthy Cities movement of the 1980s. These initiatives are designed to understand and act upon the social determinants of health, work to promoting health and wellbeing, tackle morbidities and unnecessary mortality, and lead on community action, often in partnership with health services. The author argues that these very same initiatives are essential in PC in addressing similar challenges at the EoL. They: 1) Provide a social model of health for PC; 2) Promote valuable civic engagement and partnership with clinical services in PC; and, 3) Help build and normalize cultural literacy about dying, death, and grief, and in so doing make significant contributions to tackling the co-morbidities and co-mortalities associated with life-limiting illness, caregiving and bereavement. **Abstract:** <http://bit.ly/35H2KJe>

**N.B.** Selected articles on compassionate communities noted in 2 and 9 December 2019 issues of Media Watch (#642, pp.11-12 and #643, p.7, respectively).



Would this article be of interest to a colleague?

## Provocations on privilege in palliative care: Are we meeting our core mandate?

*PROGRESS IN PALLIATIVE CARE* | Online – 18 December 2019 – While increasingly recognized as a human right, access to hospice and palliative care (PC) is still not a given. Even though PC as a concept seems to be unanimously supported, that is what it remains: an idea that only becomes reality for people privileged enough to access it. Those who do benefit tend to also benefit from high socio-economic status and family support. People who are facing the end-of-life who also face social and structural inequities like poverty, homelessness, racism, and stigma, are not so privileged. Modern day hospice and PC services are vital to ensuring high-quality care for those who are dying but such services may, albeit unintentionally, serve to privilege some people in need of PC while rendering “others” invisible. In doing so, inequities in the provision of PC have been created that challenge the very root structure from which early hospice care originated. **Abstract:** <http://bit.ly/38YWf6Q>

## Palliative care guidelines for the management of HIV-infected people in South Africa

*SOUTH AFRICAN JOURNAL OF HIV MEDICINE* | Online – 13 December 2019 – It was the general belief in the 1980s that a vaccine and cure would have been found by the end of that decade or at the latest, that is, the middle of the 1990s. That did not occur, and the HIV epidemic is now firmly rooted in southern African soil. Antiretroviral therapy has transformed the infection into a chronic, manageable disorder yet the condition remains incurable. About 8 million HIV-infected South Africans need care and will die from or with the virus. Their suffering is the concern of these guidelines as many will require palliative care (PC). The ‘total pain’ that accompanies suffering arises from multiple causes. Analgesics alone do not effectively control this pain although PC teams throughout the country’s health service would go a long way to answer this need. Even highly motivated teams require funding, organisation and the support of colleagues and government in a country where its public health is in trouble: underfunded, overcrowded, ageing facilities in need of renewal and a department facing extraordinarily high levels of litigation. Developing a discipline of PC and fitting it into this failing system at this time will be a testing experience, but it must happen. Somehow. **Full text:** <http://bit.ly/2qZqXeJ>

## Palliative care and the injustice of mass incarceration: Critical reflections on a harm reduction response to end of life behind bars

*WITNESS: THE CANADIAN JOURNAL OF CRITICAL NURSING DISCOURSE* | Online – Accessed 21 December 2019 – Due to the criminalization of marginalized people, many markers of social disadvantage are overrepresented among prisoners. With an aging population, end of life in prison thus becomes a social justice issue that nurses must contend with, engaging with the dual suffering of dying and of incarceration. However, prison palliative care (PC) is constrained by the punitive mandate of the institution and has been critiqued for normalizing death behind bars and appealing to discourses of individual redemption. The authors argue that prison PC has much to learn from harm reduction. Critical reflections from harm reduction scholars and practitioners hold important insights for prison PC: decoupled from its historical efforts to reshape the social terrain inhabited by people who use drugs, harm reduction can become institutionalized and depoliticized. Efforts to address the harms of substandard PC must therefore be interwoven with the necessarily political work of addressing the injustice of incarceration. **Abstract (w. list of references):** <http://bit.ly/36ZKYB4>

**N.B.** Click on pdf icon to access full text. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>



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

## Caring for frail older patients in the last phase of life: Challenges for general practitioners in the integration of geriatric and palliative care

*ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE* | Online – 11 December 2019 – The best possible care for frail older patients at the end of life can require the integration of geriatric and palliative approaches, possibly with different accentuations at different times. General practitioners (GPs) are particularly important in this context: they provide patients with low-threshold primary care close to their homes and provide both general palliative care (PC) and geriatric services. The results [of this study] show that GPs see the care of frail older patients at the end of their lives through: a) The growing number of older people; b) Multimorbidity and complexity of the problem areas; c) The integration of geriatric and palliative approaches; d) The high average age of general practitioners and the lack of junior staff; and, e) The problem of ensuring care in rural areas as a major challenge. The practical transition between geriatric and PC is considered by GPs to be fluid and there is a desire for more integration of both disciplines. Both approaches should be offered for a selection of patients as a combined service. In the future a systematic network between GPs and geriatricians in practices, clinics, and day clinics will be necessary. **Abstract (w. list of references):** <http://bit.ly/2RWKJ5R>

**N.B.** German language article.

Noted in Media Watch 9 October 2017 (#533, p.16):

- *CURRENT ONCOLOGY REPORTS* | Online – 2 October 2017 – ‘**Using geriatric assessment strategies to lead end-of-life discussions.**’ End-of-life (EoL) discussions with geriatric oncology patients are a vital part of the comprehensive care of the senior adult patient. Patients and caregivers may have expectations that are not concordant with what is reasonably achievable if the patient is frail. Measuring baseline cognition, nutritional status, and physical function and discussing goals of care are all essential pieces of information that can be obtained through a comprehensive geriatric assessment ... crucial in developing EoL care plans that reflect both the patient’s health status and personal values. **Abstract (w. list of references):** <http://bit.ly/34jS173>

Noted in Media Watch 17 April 2017 (#508, p.7):

- *CLINICS IN GERIATRIC MEDICINE* | Online – 6 April 2017 – ‘**Integrating quality palliative and end-of-life care into the geriatric assessment.**’ The comprehensive geriatric assessment is greatly enhanced by integration of ongoing palliative and end-of-life (EoL) care assessments. Discussions about advanced illness management and dying can improve outcomes. Common disease trajectories are evident that indicate a limited life expectancy and the need for palliative care. Common physiology and physical changes are evident, which can be used to improve palliative and EoL symptom management. Anticipation and management of the common physical, psychosocial and spiritual symptoms experienced at the EoL are vital to a quality death for older adults. **First page view:** <http://bit.ly/2Oh4SRH>

## Assisted (or facilitated) death

Representative sample of recent journal articles:

- *ANNALI*, 2019;55(4). ‘**After the Italian Constitutional Court’s ruling on the absence of criminal liability for assisted suicide: The role of ethics committees and clinical ethics.**’ The Constitutional Court handed down a judgment on 25 September 2019 following on from that Court’s Order No 207 of 24 October 2018. The issue of constitutionality of Article 580 of the Criminal Code, in the part about the punishment of the aid to suicide, was raised by the Court of Milan. According to the Court “under certain conditions, a person who facilitates the execution of the suicide intention, autonomously and freely formed, of a patient kept alive by life support treatments and affected by a irreversible pathology, source of physical or psychological suffering that he considers intolerable but fully capable of making free and conscious decisions.” According to the Court, a local ethics committee must provide an opinion in all cases involving a request for medically-assisted suicide. **Abstract:** <http://bit.ly/2ZdVXnO>

**N.B.** English language article. Click on pdf icon to access full text.

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- *CMAJ OPEN* | Online – 14 December 2019 – ‘**Quality of care with telemedicine for medical assistance in dying eligibility assessments: A mixed-methods study.**’ To facilitate access to medical assistance in dying (MAiD) in British Columbia, telemedicine has been used for eligibility assessments. Twenty-one participants (8 MAiD assessors, 1 patient, 7 support persons of patients and 5 MAiD administrators) were interviewed. Telemedicine for MAiD eligibility assessments was highly acceptable to the support persons and patient and to most assessors and administrators. Assessors expressed challenges with empathy, eye contact, non-verbal communication and missing contextual factors. Participants described which patients were appropriate and which were not. Telemedicine improved access and equity for the patients who received this service. It was perceived as an effective and efficient way to perform eligibility assessments. Concerns were expressed by assessors and administrators, but not by the patient or support persons, about confidentiality. Opinions varied on the requirement for a regulated healthcare professional to be in physical attendance with the patient to act as a witness. Updated clinical and administrative policies are needed to address barriers to telemedicine access and to best support patients and assessors using this technology. **Full text:** <http://bit.ly/2LYp6Ou>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 16 December 2019 – ‘**Medical aid in dying, hastened death, and suicide: A qualitative study of hospice professionals’ experiences from Washington State.**’ Three primary themes were identified from the interviews [with 21 home hospice professionals (seven nurses, seven social workers, four physicians, and three chaplains)]: 1) Dealing with and differentiating between hastened death and suicide; 2) Medical aid in dying access and affordability; and, 3) How patients have hastened their own deaths. Analysis of these data indicates that there are some patients receiving hospice services who die by suicide because they are not eligible for, have no knowledge of, or lack access to legalized medical aid in dying. Hospice professionals do not consistently identify patients’ deaths as suicide when they are self-inflicted and sometimes view these deaths as justified. Suicide and hastened deaths continue to be an unexamined cause of death for some home hospice patients who may have requested medical aid in dying. Open communication and increased education and training is needed for palliative care professionals regarding legal options, issues of suicide, and suicide assessment. **Abstract (w. link to references):** <http://bit.ly/2PrIve9>

## [Publishing Matters](#)

### **Predatory publishing, hijacking of legitimate journals and impersonation of researchers via special issue announcements: A warning for editors and authors about a new scam**

*AUSTRALASIAN PHYSICAL & ENGINEERING SCIENCES IN MEDICINE* | Online – 16 December 2019 – The current world of academic publication is plagued with stories of predatory publishing, journal hijacking, and the like, with much discussion. Recently, several proposals have been received by this journal for a Special Issue. The proposals are sometimes well written and appear to come from well credentialed researchers, using the email addresses of the said researchers, with links to valid web profiles. On one occasion the proposers were asked to provide more detailed information on various aspects of the proposal, and they did so promptly and professionally. However, there is a catch to these proposals; the email addresses being used to represent the proposed special issue editors have very slight changes (e.g., insertion of a single letter in the middle of the name, replacement of a full-stop with a dash, etc.) indicating that the apparent proposers are actually being impersonated. The impersonators seek Special Issue announcements in legitimate journals, using the false email accounts. Any correspondence and enquiries regarding the special issue would then go to the fake email address rather than the real researchers. Presumably the aim of this practice is to use the fake email addresses, along with the real names of the impersonated editors and the journal itself, as a point of contact to collect money from enquiring authors. **Full text:** <http://bit.ly/35zxSdK>



## 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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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.

**[Search Back Issues of Media Watch @ http://bit.ly/2ThijkC](http://bit.ly/2ThijkC)**

## Media Watch: Access on Online

### **International**



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2OVQyP3>

[Scroll down to 'Media Watch: The Homeless']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU> ]

### **Asia**

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2G2iqko>

[Scroll down to 'Resource Collection' and 'Media Watch Barry Ashpole']

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### **Australia**

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

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

### **Canada**



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

### **Europe**



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2XC24jA>

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

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

### **South America**

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

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