

## 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

**When family caregivers are not intellectually or emotionally prepared or physically capable, the caregiver is at high risk for serious health issues and cognitive, emotional, and physical decline particularly as caregiving extends over time.**

**'A review of the complex role of family caregivers as health team members and second-order patients' (p.6), in *Healthcare*.**

## Canada

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- GLOBAL TV NEWS | Online – 25 April 2019 – **'Nearly 7,000 Canadians have died with medical assistance: Health Canada.'** According to the latest interim report, 6,749 people have received medically assisted deaths That amounts to roughly one per cent of all deaths in Canada. Health Canada says assisted deaths were provided primarily by physicians, with less than 10% provided by nurse practitioners. Only six people have opted to self-administer drugs to end their lives. The setting for assisted deaths has been divided primarily between hospitals and patients' homes, with cancer-related illness the most frequently cited reason for seeking the service. The report does not include any country-wide statistics on how many Canadians have been denied medical assistance in dying because only a handful of provinces report that information. However, the report says the most commonly cited reasons for denying a request for assisted death were "loss of competency" and that the patient's natural death was not "reasonably foreseeable," as required by law. <http://bit.ly/2IZnBiG>

'Fourth Interim Report on Medical Assistance in Dying in Canada,' Health Canada, April 2019. **Download/view at:** <http://bit.ly/2Dzz5Wg>

- ALBERTA | CBC News (Edmonton) – 23 April 2019 – **'CBC Edmonton investigation on assisted dying wins Edward R. Murrow Award.'** CBC Edmonton investigative reporter Jennie Russell has won a prestigious Edward R. Murrow Award for an investigation that revealed the troubling human cost of Covenant Health's medical-assistance-in-dying policy. The series of stories detailed how the policy, by default, prohibited patients from even signing their medical-assistance-in-dying (MAiD) request forms, or undergoing eligibility assessments by provincial medical staff, on Covenant's publicly funded properties. The Catholic health provider also expressly prohibits assisted deaths from taking place in its facilities. The stories detailed how Covenant's policy had a traumatic effect on some terminally ill patients

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and their families... Ethics and legal experts said the policy, which the provincial government allowed, was not only cruel and inhumane but infringed on patients' rights. The stories drew outrage nationwide and sparked a discussion about the rights of publicly funded religious health providers. Under public and political pressure, Covenant Health revised its policy and now unconditionally allows patients to sign their MAiD forms and undergo their assessments in its facilities. <http://bit.ly/2GwBVfs>

**N.B.** Links to the article in the CBC series embedded in the CBC report.

## [U.S.A.](#)

### **Guantánamo Bay as nursing home: Military envisions hospice care as terrorism suspects age**

*THE NEW YORK TIMES* | Online – 27 April 2019 – Nobody has a dementia diagnosis yet, but the first hip and knee replacements are on the horizon. So are wheelchair ramps, sleep apnea breathing masks, grab bars on cell walls and, perhaps, dialysis. Hospice care is on the agenda. More than 17 years after choosing the American military base in Cuba as “the least worst place” to incarcerate prisoners from the battlefield in Afghanistan, after years of impassioned debates over the rights of the detainees and whether the prison could close, the Pentagon is now planning for terrorism suspects still held in the facility to grow old and die at Guantánamo Bay. With the Obama administration’s effort to close the prison having been blocked by Congress and the Trump administration committed to keeping it open, and with military trials inching ahead at a glacial pace, commanders were told last year to draw up plans to keep the detention center going for another 25 years, through 2043. At that point, the oldest prisoner, if he lives that long, would be 96. <https://nyti.ms/2W8T2KT>

Noted in Media Watch 11 June 2018 (#567, p.2):

- *THE MIAMI HERALD* | Online – 6 June 2018 – ‘**Guantánamo commanders make pitch for new prison with hospice-care wing for ex-CIA captives.**’ The U.S. military’s mission at Guantánamo is shifting to permanent detention for al-Qaida and other war-on-terror detainees, commanders told reporters in a rare public pitch for Congress to fund a new \$69 million, wheelchair-accessible prison – complete with a hospice-care cellblock – for the five accused 9/11 plotters and 10 other captives. “Picture in your mind elderly detainees, brothers taking care of one another. That is the humane way ahead,” said prison spokeswoman Navy Commander Anne Leanos. <https://hrlid.us/2VvISqL>

**N.B.** A compilation of selected articles, reports, etc., on end-of-life care in the prison system noted in past issues of the weekly report is posted on the Palliative Care Network website. **Download/view at:** <http://bit.ly/2RdegnL>

### **Stories about palliative care and the end of life are universal — and sorely needed**

CALIFORNIA | Center for Health Journalism (University of Southern California) – 24 April 2019 – Patients’ view of palliative care (PC) is often shaped by the media: what they hear or read in the news, or see on medical dramas on television, Dr. Sunita Puri said. The medical director for PC at the Keck Medical Center and Norris Cancer Center of the University of Southern California suggested reporters follow patients from diagnosis to death, describing along the way the decisions someone might face at every stage. Journalists would do well to focus their coverage less on “medical miracles” and more on the realities most patients face at the end of life. She emphasized the humility that comes from sitting in silence and listening to someone’s story, asking them about their life and how it has been changed by this disease. For reporters, proceeding with sensitivity is crucial. Puri suggested asking the patient if there are certain topics that are off limits. Ask them how they would describe the state of their health now, an important insight into their mindset. Sometimes asking permission to use scary words can be helpful: “Would it be OK if I used the word ‘dying’ with you?” In her own reporting, Smith said she was blown away by how open hospice patients were, allowing her to walk into their homes and hear their stories. The experience forever changed her. <http://bit.ly/2UEI6ml>

## Caring for relative and fear you'll make mistake?

CALIFORNIA | *The Sacramento Bee* – 22 April 2019 – About a quarter of the nation's 40 million family caregivers (FCGs) live with the fear that they will make a mistake on vital medical tasks such as giving injections or caring for wounds that could harm their loved ones, according to an American Association for Retired Persons report.<sup>1</sup> "Many of the changes in the healthcare system, such as earlier discharge and chronic disease self-management, carry major expectations for families to step up to more complex care and involvement. Yet, too often they are unprepared and do not get the support they need to assume these important roles," said Heather Young, at the Betty Irene Moore School of Nursing at the University of California, Davis. "This report provides direction for future action to improve the lives and capacity of FCGs." The report, which Young co-authored, was done to provide healthcare workers and policymakers with a better understanding of the experience of FCGs and with recommendations on how to better support them. The first step, Young said, is raising awareness that FCGs play a crucial role in the medical care team, and once healthcare providers embrace this, they will come to understand that they must change how they interact with caregivers. About half of the nation's 40 million FCGs perform medical or nursing tasks for their loved ones at home, Young and other

researchers found, and the other half take care of non-medical tasks such as grooming, bathing or dressing a loved one. Of those who handle medical care, eight out of 10 administer medication, half prepare special diets and assist with mobility devices, and four in 10 perform wound care. <http://bit.ly/2XrYUik>

### Extract from American Association for Retired Persons report

Caregivers continue to take on the responsibilities that used to be the purview of healthcare professionals; they are providing complex care that they often find difficult to perform. More than half the caregivers who perform medical/nursing tasks are performing three or more of them. They provide this care in the context of multiple health conditions, serious illness, and palliative care. The context matters for understanding the experience of FCG and tailoring appropriate support.

### [Specialist Publications](#)

'A review of the complex role of family caregivers as health team members and second-order patients' (p.6), in *Healthcare*.

1. 'Home Alone Revisited: Family Caregivers Providing Complex Care,' American Association for Retired Persons, April 2019. **Download/review at:** <http://bit.ly/2UyvRli>

Noted in Media Watch 15 April 2019 (#610, p.2):

- REUTERS HEALTH NEWS | Online – 10 April 2019 – '**Few family caregivers get formal training.**' Less than one in 10 family caregivers (FCGs) receive training for assisting older adults with disabilities, a U.S. study suggests.<sup>1</sup> Just 7.3% of the 1,861 caregivers studied received any training. The study wasn't designed to prove whether education or training might directly improve outcomes for caregivers or for their adult charges. It also wasn't designed to assess what type of education might be most beneficial, or which caregivers might need the most training to assist loved ones at home. Still, the results highlight a missed opportunity to improve patient care.<sup>2</sup> <https://reut.rs/2UyjcKv>
  1. 'Factors associated with receipt of training among caregivers of older adults,' *JAMA Internal Medicine*, published online 8 April 2019. **Abstract:** <http://bit.ly/2Z6feY4>
  2. 'Family caregivers needed – no training provided,' *JAMA Internal Medicine*, published online 8 April 2019. **Abstract:** <http://bit.ly/2leAo13>

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Noted in Media Watch 18 February 2019 (#602, p.13):

- **MEDSCAPE** | Online – 13 February 2019 – ‘**Dying at home: The burden of medication management.**’ A recent literature review explored the experiences and perspectives of family caregivers in managing medications for a family member being cared for and dying at home.<sup>1</sup> The authors reviewed 15 studies in this area and synthesized the findings into five key themes that provide a framework to improve support for these caregivers: These concepts provide important perspectives on caregiver fears, such as overmedicating the patient, and challenges in understanding instructions, particularly with multiple medications. **Full text:** <https://wb.md/2X43MeD>
  1. ‘Managing medicines for patients dying at home: A review of family caregivers’ experiences.,’ *Journal of Pain & Symptom Management*, published online 11 September 2018 (noted in 17 September 2018 issue of Media Watch, #581, p.12). **Full text:** <http://bit.ly/2tli8t8>

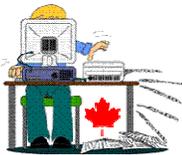
### Healthcare fellows learn the tough task of discussing death and dying

PENNSYLVANIA | *The Pittsburgh Post-Gazette* – 22 April 2019 – Each Monday night for eight weeks, the group of aspiring physicians, pharmacists, social workers, medical ethicists and other future healthcare professionals met for three hours to talk about death – for the purpose of being better able to talk about death. The 33 post-graduate students and other trainees spent time at a residential hospice, hospital and nursing home. They heard from palliative care doctors, geriatricians and other specialists. They talked with relatives of those who had died. They practiced end-of-life (EoL) conversations with one another. And by their last meeting this month, the participants in the Death & Dying Fellowship of the Jewish Healthcare Foundation learned how to broach a difficult topic with terminally ill patients and those individuals’ loved ones – a topic for which their formal studies typically provided minimal preparation. Some 2.7 million Americans die each year, and most die under medical supervision in a hospital or nursing home rather than in their own residence. Those who die at home have frequently been hospitalized late in life themselves. So most individuals have interacted with medical professionals before death, but the fellowship program’s instructors say both sides often ignore EoL discussion, such as how much intensive treatment a patient would want if there’s minimal chance of benefit. <http://bit.ly/2DsyNRj>

### Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEVADA | Associated Press (Carson City) – 23 April 2019 – ‘**Medical dying bill fails in Nevada Senate.**’ A Nevada bill that would allow terminal patients to kill themselves with medication prescribed by a doctor has failed. The state Senate failed to take a vote on the measure ahead of a legislative deadline that decides whether bills move on. <http://bit.ly/2VpgJl2>



#### [Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I’ve applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>



Media Watch: Behind the Scenes  
<http://bit.ly/2MwRRAU>

## International

### **Benchmarks for aged care work conditions urgent: Experts**

AUSTRALIA (New South Wales) | University of Sydney – 24 April 2019 – The introduction of 12 weeks of paid end-of-life leave for carers and including superannuation in paid parental leave are among a suite of research-informed policy recommendations detailed in a report by the Work & Family Policy Roundtable – a multi-disciplinary network of more than 32 experts from 17 universities – calling for reform of the national policy settings of work, care and family policies ahead of the Federal election. Australia's public expenditure on long term care is currently at 1% of GDP compared to the OECD average of 1.8%, highlights Associate Professor Elizabeth Hill from the University of Sydney, the roundtable's co-convenor. "The shocking stories emerging from the aged care royal commission stress the urgent need for reform," Associate Professor Hill said. "Australia would be in a much better position to deliver a sustainable and high-quality care system if public investment in care infrastructure was increased by an addi-

tional 2% of GDP expenditure. Our research shows current funding models underwrite fragmented and insecure work in frontline care work. We need to shift the dial so that Australia's care." **Download/review 'Work, Care & Family Policies: Election Benchmarks 2019' at: <http://bit.ly/2JtRf8>**

#### **Specialist Publications**

**'Mentoring stages: A study of undergraduate mentoring in palliative medicine in Singapore'** (p.11), in *Plos One*.

**'Legislating the right-to-die with dignity in a Confucian society: Taiwan's Patient Right to Autonomy Act.'** (p.12), in *Hastings International & Comparative Law Review*.

### **Hospice Africa Uganda lays off staff**

AFRICA (Uganda) | *New Vision* (Kampala) – 23 April 2019 – Hospice Africa Uganda (HAU) has announced a downsizing of its staff at their Mbarara and Kampala centres due to a critical cash shortfall. The Kampala-based charity, which has provided palliative care services in Uganda since 1993 was left with no choice given the fall-off in financial support from institutional and individual donors. The hospice's chair, Joan Kelly, said the decision to lay off staff was difficult: "Sadly, as with so many other charities, funding has been a huge challenge for HAU in the last few years and we had to lay off staff in the last week at two of our three centres in Mbarara and Kampala to ensure we survive. There has been no change in our operations in Hoima." Consequently, HAU founder, Dr. Anne Merriman, who was nominated for a Nobel Peace for her work in the hospice, is appealing for help. <http://bit.ly/2UzSqfE>

## **Specialist Publications**

### **Early identification of pediatric neurology patients with palliative care needs: A pilot study**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 April 2019 – Palliative care (PC) services are beneficial for pediatric neurology patients with chronic, life-limiting illnesses. However, timely referral to PC may be impeded due to an inability to identify appropriate patients. A random subset of pediatric neurology patients were screened for number of hospital admissions, emergency center visits, and problems on the problem list. Screening results led to the hypothesis that having six or more hospital admissions in one year indicated unmet PC needs. Next, hospital admissions in the past year were counted for all patients admitted to the neurology service during a six-month period. Patients with six or

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more admissions as well as age- and gender-matched controls were assessed for unmet PC needs. In hospitalized pediatric neurology patients, having six or more admissions in the preceding year did not predict unmet PC needs. While this pilot study did not find a quantitative measure that identifies patients needing a PC consultation, the negative finding highlights an important distinction between unmet social needs that interfere with care and unmet PC needs. **Abstract:** <http://bit.ly/2W4ABqO>

### **A review of the complex role of family caregivers as health team members and second-order patients**

*HEALTHCARE* | Online – 24 April 2019 – In palliative care, the unit of care is the patient and their family. Although members of the health care team often address the family caregiver's (FCGs) opinions and concerns, the focus of care remains on the needs of the patient. The readiness and willingness of the family caregiver is often overlooked as they are expected to assume a complex caregiving role. When FCGs are not intellectually or emotionally prepared or physically capable, the caregiver is at high risk for serious health issues and cognitive, emotional, and physical decline particularly as caregiving extends over time. FCGs are often a neglected and at-risk population. This article addresses the complex role of FCGs, as both health team members and second-order patients. It emphasizes the importance of family assessment and interventions to balance the burdens and benefits of family caregiving and protect caregivers' health and well-being. **Abstract:** <http://bit.ly/2GOdXxH>

### **Later life care planning and concerns of transgender older adults in Canada**

*INTERNATIONAL JOURNAL OF AGING & HUMAN DEVELOPMENT* | Online – 18 April 2019 – While the particular healthcare concerns of transgender people have been documented and transgender aging is an emerging area of scholarship, little is known about planning for later and end-of-life care among transgender older adults. As part of a larger project, focus groups and interviews were conducted with 24 transgender older adults (average age 70 years) living in five cities in Canada exploring their concerns and explicit plans for later life care. Three primary themes emerged: 1) "Dealing with the day-to-day" reflecting economic precarity and transitioning in later life; 2) Fractures and support within family and community; and, 3) "There's a huge gap between principle and practice" reflecting mixed experiences and perceptions of healthcare services. These themes suggest that effective promotion of care planning among older transgender persons requires an appreciation of the daily exigencies of their lives and the extent and nature of social support available to them. **Abstract:** <http://bit.ly/2UQOwEj>

### **The right to grieve**

*JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2019;321(16):1569-1570. While the close family circle is accorded the right to grieve by society, the nature of the patient-physician relationship is not acknowledged to the same extent. Death of a patient can induce shame, self-doubt, and fear of lawsuit or judgment from peers to be inadequate, which can further isolate the physician and may increase the risk of unresolved emotions and maladaptive coping. Despite an increasing emphasis on empathic care of the dying as a core competency to master during training, very little formal training is offered in coping skills for the emotions that arise from the care of a dying patient. Residents may develop symptoms of posttraumatic stress disorder after patient death, with an increasing frequency as the level of training increases. While attending physicians are expected to provide support for physician trainees through the experience of a patient death, they may not always be able to do so because they are sometimes in need of support themselves. Even palliative care specialists who are considered "experts in death" may suffer silently, unable to reach out for support. Some physicians think about quitting clinical medicine after an emotional death of a patient, and maladaptive coping, such as avoidance of emotion and substance abuse, exists through all stages of medical training and practice. This may be perpetuated and exacerbated by the culture of medicine where physicians who cry risk being considered unprofessional, weak, or emotionally unstable. **Full text:** <http://bit.ly/2UD3ljw>

## Shared decision making and the importance of time

*JOURNAL OF AMERICAN MEDICAL ASSOCIATION* | Online – 19 April 2019 – Uncertain evidence and the uniqueness of a patient's healthcare issues often make it difficult to identify the best course of care. These instances are becoming increasingly common as more people live longer with multiple chronic conditions and care becomes more complicated. Clinical decisions may involve screening or treatment with new toxic drugs in older patients; timely use of adjuvant, palliative, or pain care; or prioritizing care at the end of life. Shared decision making is essential in the care of patients in these complicated situations. For clinicians, being able to and choosing to spend time on understanding what truly matters to patients when making decisions together is an achievement that makes the work of clinicians meaningful and rewarding. The most common barrier to shared decision making, cited by patients and clinicians, is time. **Full text:** <http://bit.ly/2XANLMs>

## Profanities, promises, and hospices

*JOURNAL OF CLINICAL ONCOLOGY* | Online – 29 April 2019 – Although oncology fellows gain significant exposure to end-of-life discussions, fewer than half of oncology fellows benefit from structured rotations on palliative care services. Even with such rotations, it is unclear how involved oncology fellows (or oncologists in general) remain with their patients' transitions to hospice. The result is that out hospice-bound patients inevitably fade from our memories, re-emerging with a shock only when we are reminded of them and guilty by our abrupt disconnection. In my case, the shock came from meeting Ms. D.'s profanity-loving twin. In an earlier case, the shock came from clearing out old e-mails involving former patients. The recipient of those e-mail-derived shocks, also an oncology

fellow at the time, astutely concluded that we have both the privilege and the responsibility to stay connected with our patients until their journeys reach their end. This realization presupposes a truth that I had overlooked: hospice is not the end destination or disposition for my oncology patients but merely part of their journey. **Full text:** <http://bit.ly/2IZVwaP>



Would this article be of interest to a colleague?

## Ethics of crisis sedation: Questions of performance and consent

*JOURNAL OF MEDICAL ETHICS* | Online – 20 April 2019 – This article focuses on the practice of injecting patients who are dying with a relatively high dose of sedatives in response to a catastrophic event that will shortly precipitate death, something that termed “crisis sedation.” The authors first present a confabulated case that illustrates the kind of events they have in mind, before offering a more detailed account of the practice. They then comment on some of the ethical issues that crisis sedation might raise. The authors identify the primary value of crisis sedation as allowing healthcare professionals to provide some degree of reassurance to patients, their families and the professionals who are caring for them. Next they focus on the issue of informed consent. Finally, the authors ask whether continuous deep sedation might be preferable to crisis sedation in scenarios where potential catastrophic events can be anticipated. **Abstract:** <http://bit.ly/2GpuS8v>

### Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 20 April 2019 – ‘**Deep continuous patient-requested sedation until death: A multi-centric study.**’ In 2016, a new law was adopted in France granting patients the right, under specific conditions, to continuous deep sedation until death (CDSUD). This study highlights the low rate of request and the even lower rate of CDSUD in specialised palliative care. However, the sedation for psycho-existential distress and the lack of procedure records raise ethical questions. **Abstract:** <http://bit.ly/2KVWTtF>

**N.B.** Additional articles on palliative or terminal sedation noted in 25 February 2019 issue of Media Watch (#603, p.7).

## Perspectives on volunteer-professional collaboration in palliative care: A qualitative study among volunteers, patients, family carers and healthcare professionals

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 April 2019 – Governments intend to meet resource constraints in professional palliative care (PC) by stimulating informal care, including volunteerism. However, little is known about current volunteer-professional collaboration. Such insights are relevant for future policy development regarding volunteer efficiency, quality of care and the capacity of volunteer care to support healthcare services and professionals. A qualitative study was conducted with volunteers, nurses, psychologists and family physicians, and with people with serious illnesses and with family carers. Participants were recruited from hospital, home-care, day-care and live-in services in Flanders, Belgium. Volunteers are in the front line of PC provision and therefore collaborate intensely with nurses, particularly in dedicated PC services. However, collaboration with other professionals is limited. The presence and availability of nurses was found to be crucial for volunteers, both for support and to achieve integration through collaboration. **Abstract (w. link to references):** <http://bit.ly/2UVZF6T>

Noted in Media Watch 10 December 2018 (#593, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 7 December 2018 – ‘**The liminal space palliative care volunteers occupy and their roles within it: A qualitative study.**’ Volunteers have an important place in palliative care (PC), positively influencing quality of care for seriously ill people and those close to them and providing a link to the community. However, it is not well understood where volunteers fit into PC provision or how to support them adequately. The authors describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people. Two volunteer roles were identified. The first was “being there” for the dying person. The second was the “liaison” role. **Abstract:** <http://bit.ly/2XEMioy>

## Changes over time in good-parent beliefs among parents of children with serious illness: A two-year cohort study

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 23 April 2019 – Parents of seriously ill children hold personal beliefs about what they should do to be good parents. How these beliefs change over time is unknown. The authors used latent transition models (LTM) to classify parents into groups with similar good-parent beliefs during the baseline and follow-up periods, and modeled the change in good-parent beliefs over time as a function of covariates using generalized linear mixed models. Two parent belief profiles emerged: Loved (“Making sure my child feels loved”, n=61 at baseline) and Informed (“Making informed decisions”, n=63 at baseline). At 12 months, 21 parents (20.4%) had moved into the Loved group and no parents transitioned to the Informed group. By 24 months, 8 parents transitioned to the Loved group and 4 to the Informed group (13.04%). Transition into the Loved group was associated with parents’ baseline degree of hopeful thinking and positive perceptions of child’s health at baseline. Some parents change their parenting priorities over time. Hopeful patterns of thinking and perception of child health appear to predict change. Clinicians should regularly reevaluate

good-parent beliefs over time to promote priority-congruent dialogue. **Abstract (w. link to references):** <http://bit.ly/2ZvU5Xj>

### Coming “home”: Place bonding for parents accessing or considering hospice based respite

*HEALTH & PLACE*, 2019;57:101-106. Little literature examines the cognitive journey taken by parents considering/receiving hospice care for their child. A constructivist grounded theory study explored 38 parents’ views of considering/using a children’s hospice. Data analysed from focus groups and interviews identified three main concepts. The focus of this paper is identified as coming “home.” This concept depicts the desire and the sense of searching that parents experienced in trying to find a place, other than their actual home, where their child could access a caring environment and their parents received some respite from caregiving. Despite there being a paradox associated with hospice-based respite, once they had crossed the threshold the parents bonded with the place and experienced rootedness and familiarity. The hospice became a place of living and belonging; a place where they could “come home.” **Abstract:** <http://bit.ly/2UXtP9Y>

## End-of-life care in Canada

### **Community palliative care initiatives to reduce end-of-life hospital utilization and in-hospital deaths: A population-based observational study evaluating two home care interventions**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 22 April 2019 – The end-of-life period is characterized by increased hospital utilization despite patients' preferences to receive care and die at home. This was an ecologic and retrospective cohort study of palliative home care patients in southeastern Ontario [Canada] to evaluate the impact of interventions aimed at planning for a home death (Yellow Folder) and managing symptoms in the home (Symptom Response Kit) on place of death and hospital utilization among palliative home care patients. The proportion of patients who died in the community increased after implementation of the interventions, from 42.8% to 48.5%. Compared to patients who received neither intervention, patients who received the Yellow Folder or Symptom Response Kit had an increased likelihood of dying in the community, with the largest relative risk observed in patients who received both interventions. Receipt of these interventions was only associated with reductions in hospitalizations or emergency department visits in the six months prior to death. **Abstract (w. link to references):** <http://bit.ly/2USnL28>

## End-of-life care in Belgium

### **Are we evolving towards greater and earlier use of palliative home care support? A trend analysis using population-level data from 2010-2015**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 April 2019 – This population-level study found a slight trend towards more and earlier initiation of palliative home care support (PHCS) between 2010 and 2015. However, uptake of PHCS remained below estimated needs in the population and the proportion of people receiving PHCS very late in life remained stable over time. Uptake of PHCS increased from 31.7% to 34.9% between 2010 and 2015. Trends were similar in size for all [patient] groups [studied], except for people who died from dementia... The timing of initiating PHCS advanced from 41 days to 46 days before death, with the smallest increase observed among people who died from dementia. The proportion of people receiving PHCS only in the last week of life changed from 15.3% to 13.9%. **Abstract (w. link to references):** <http://bit.ly/2Uym70B>

### **Interprofessional team member communication patterns, teamwork, and collaboration in pre-family meeting huddles in a pediatric cardiac intensive care unit**

*JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 17 April 2019 – Interprofessional teams often develop a care plan prior to engaging in a family meeting in the pediatric cardiac intensive care unit (CICU) – a process that can affect the course of the family meeting and alter team dynamics, but that has not been studied. In this prospective observational study in a pediatric CICU [at a children's hospital in Philadelphia, Pennsylvania] physicians spoke for an average of 83.9% of each meeting's duration; non-physicians averaged 9.9%. Teamwork behaviors were present and adequately performed as judged by trained observers. Significant differences in physician and non-physician perceptions of collaboration were found in 3 out of 10 observed meetings. Interprofessional team members' interactions in team meetings provide important information about team dynamics, revealing potential opportunities for improved collaboration and communication in team meetings and subsequent family meetings. **Abstract (w. link to references):** <http://bit.ly/2URQ3u1>



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

## Special Issue on medical cannabis use in palliative care

*JOURNAL OF PALLIATIVE MEDICINE* | Online – Accessed 22 April 2019 – Patients are aware that medical cannabis and cannabinoid derivatives are available to treat pain and symptoms. However, the medical literature to guide palliative medicine physicians in recommending its use is not yet well developed. The special issue brings together the best medical information available. The goal is to supply helpful information to clinicians and to provide the foundation for future research in the exploration of cannabis use in palliative care. The special issue is scheduled to be published in October 2019. **Preview (available through 6 May 2019):** <http://bit.ly/2ZnoHuh>



Noted in Media Watch 21 January 2019 (#598, p.9):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 14 January 2019 – ‘**Top ten tips palliative care clinicians should know about medical cannabis.**’ Palliative care providers are being asked to consider medical cannabis (MC) as part of symptom-directed treatment regimens although many providers have limited experience recommending MC and were trained before it was commercially available. This article seeks to dispel myths about MC and provides a balanced view of the benefits and burdens of this therapeutic option, providing evidence where it exists and offering practicing clinicians guidance on conditions in which MC is likely to be helpful or burdensome. **Abstract:** <http://bit.ly/2GEKogE>

Noted in Media Watch 8 October 2018 (#584, p.12):

- *JOURNAL OF CACHEXIA, SARCOPENIA & MUSCLE*, 2018;9(2):220-234. ‘**Systematic review and meta-analysis of cannabinoids in palliative medicine.**’ Following the Grading of Recommendations Assessment, Development & Evaluation methodology, no recommendations can be made for the use of cannabinoids in palliative care (PC) treatment for cancer, HIV-AIDS, or dementia. In view of this finding, further research is urgently needed to identify the efficacy and safety of cannabinoids as adjunctive or complementary therapies and to provide evidence-based recommendations on their clinical utility in PC. **Full text:** <http://bit.ly/2WeCpOd>

**N.B.** Additional articles on cannabinoids in palliative medicine noted in this issue of Media Watch.

## Clinicians’ comfort levels low with life expectancy discussions

*MEDSCAPE* | Online – 24 April 2019 – [In the U.S.] fewer than half of physicians, nurses, and advanced practice registered nurses (APRNs) report always or frequently having end-of-life discussions with older patients with chronic illnesses, according to a recent Medscape poll. The providers also say many patients put off the discussions as well. Among physicians, 42% said they always or frequently had the discussions, and 48% of nurses and APRNs answered that way. Answers differed with the age of the provider. Among physicians younger than 55 years, 39% said they always or frequently had the discussions, but the practice was much more common among physicians aged 55 years or older. In that group, 63% said they always or frequently had the talks. Among nurses/APRNs younger than 55 years, 44% said they frequently or always had the discussions, but the increase was less pronounced (54%) than among physicians for those aged 55 or older. The poll was taken in light of two recent articles about how and when patients wanted to talk about their life expectancy and how to approach such conversations with patients.<sup>1,2</sup> **Full text:** <https://wb.md/2DysDii>

1. ‘Older adults’ preferences for discussing long-term life expectancy: Results from a national survey,’ *Annals of Family Medicine*, 2018;16(6):530-537 (noted in 3 December 2018 issue of Media Watch, #592, p.11) **Full text:** <http://bit.ly/2IU4W7C>
2. ‘Softening our approach to discussing prognosis,’ *JAMA Internal Medicine*, published online 19 November 2018 (noted in 28 November 2018 issue of Media Watch, #591, p.9). **Introductory paragraph:** <http://bit.ly/2DHS9C7>

## **Non-specialist palliative care: A principle-based concept analysis**

*PALLIATIVE MEDICINE* | Online – 24 April 2019 – Building palliative care (PC) capacity among all healthcare practitioners caring for patients with chronic illnesses, who do not work in specialist PC services (i.e., non-specialist PC), is fundamental in providing more responsive and sustainable PC. Varying terminology such as “generalist,” “basic” and “a palliative approach” are used to describe this care but do not necessarily mean the same thing. Internationally, there are also variations between levels of PC which means that non-specialist PC may be applied inconsistently in practice because of this. Thus, a systematic exploration of the concept of non-specialist PC is warranted. In this literature review, the essential attributes of non-specialist PC were identified but were generally poorly measured and understood in practice. This concept is strongly associated with quality of life, holism and patient-centred care, and there was blurring of roles and boundaries particularly with specialist PC. Non-specialist PC is conceptually immature, presenting a challenge for healthcare practitioners on how this clinical care may be planned, delivered and measured. **Abstract:** <http://bit.ly/2vnc8Ba>

### **PDQ Supportive & Palliative Care Editorial Board**

## **Depression: Health Professional Version**

*PDQ CANCER INFORMATION SUMMARIES* | Online – 18 April 2019 – This PDQ cancer information summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about cancer-related depression and suicide risk in both the adult and the pediatric population. It is intended as a resource to inform and assist clinicians who care for cancer patients. It does not provide formal guidelines or recommendations for making health care decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive & Palliative Care Editorial Board, which is editorially independent of the National Cancer Institute (NCI). The summary reflects an independent review of the literature and does not represent a policy statement of NCI or the National Institutes of Health. **Full text (via PubMed):** <http://bit.ly/2IDsxKu>



### **Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation**

## **Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis**

*PLOS MEDICINE* | Online – 23 April 2019 – This study found consistent evidence from high-income countries that low socioeconomic position (SEP) is a risk factor across several components of service use at the end of life (EoL), including dying in hospital rather than at home, receiving acute hospital-based care in the last 3 months of life, and not receiving specialist palliative care (SPC) in the last year of life. The authors also found evidence of a pervasive social gradient in place of death and use of SPC. These findings should stimulate widespread efforts to reduce socioeconomic inequality towards the EoL. All research on care received towards the EoL should attempt to account for SEP, EoL care interventions should be analysed for their different effects across the social strata, and the planning and provision of EoL care services should consider SEP in local populations. **Full text:** <http://bit.ly/2GsS4ma>

## **Mentoring stages: A study of undergraduate mentoring in palliative medicine in Singapore**

*PLOS ONE* | Online – 24 April 2019 – Mentoring nurtures a mentee’s personal and professional development. Yet conflation of mentoring approaches and a failure to contend with mentoring’s nature makes it difficult to study mentoring processes and relationships. This study aims to understand of mentee experiences in the Palliative Medicine Initiative (PMI). The PMI uses a consistent mentoring approach amongst a homogeneous mentee population offers a unique opportunity to circumnavigate conflation of practices and the limitations posed by mentoring’s nature. The data will advance understanding of mentoring pro-

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cesses. The six stages of mentoring are the “pre-mentoring stage,” “initial research meetings,” “data gathering,” “review of initial findings,” “manuscript preparation” and “reflections.” These sub-themes sketch the progression of mentees from being dependent on the mentor for support and guidance, to an independent learner with capacity and willingness to mentor others. Each sub-theme is described as stages in the mentoring process (mentoring stages) given their association with a specific phase of the research process. Mentoring processes also pivot on effective communication which are influenced by the mentor’s characteristics and the nature of mentoring interactions. **Full text:** <http://bit.ly/2ZxQA2L>

### **The contagion of optimism: The relationship between patient optimism and palliative care clinician overestimation of survival among hospitalized patients with advanced cancer**

*PSYCHO-ONCOLOGY* | Online – 24 April 2019 – Clinicians frequently overestimate survival time among seriously ill patients, and this can result in medical treatment at end of life that does not reflect the patient’s preferences. Little is known, however, about the sources of clinicians’ optimistic bias in survival estimation. Related work in social networks and experimental psychology demonstrates that psychological states – such as optimism – can transfer from one person to another. The authors directly observed and audio recorded 189 initial inpatient palliative care (PC) consultations among hospitalized patients with advanced cancer. Patients self-reported their level of trait optimism and expectations for survival prognosis prior to the PC consultation, and the PC clinicians rated their expectations for the patient’s survival time following the initial conversation with the patient. They followed patient mortality for 6 months. Patient optimism was associated with clinician overestimation of their survival in a dose-response relationship. Clinicians were approximately three times as likely to overestimate the survival of patients endorsing both high trait optimism and optimistic ratings of their survival time compared with neither. **Abstract:** <http://bit.ly/2L5IFYs>

Noted in Media Watch 25 March 2019 (#607, pp.14-15):

- *SUPPORTIVE CARE IN CANCER* | Online – 13 March 2019 – ‘**Prognostication in advanced cancer: Update and directions for future research.**’ The most common prognostic approach is clinician prediction of survival (CPS) using temporal, surprise, or probabilistic questions. The surprise and probabilistic questions may be more accurate than the temporal approach... Prognostic models such as the Glasgow Prognostic Score, Palliative Performance Scale, Palliative Prognostic Score, Palliative Prognostic Index, or Prognosis in Palliative Care Study predictor model may augment CPS. However, care must be taken to select the appropriate tool since prognostic accuracy varies by patient population, setting, and time frame of prediction. **Abstract (w. list of references):** <http://bit.ly/2UFe8Qv>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT*, 2019;57(2):233-240. ‘**Palliative care clinician overestimation of survival in advanced cancer: Disparities and association with end-of-life care.**’ This is a multi-site study of 230 hospitalized patients who consulted with palliative care (PC)... The authors asked the consulting PC clinician to make their “best guess” about the patients’ “most likely survival time, assuming that their illnesses are allowed to take their natural course.” 41% of clinicians’ predictions were accurate. Among inaccurate prognoses, 85% were overestimates. Overestimation is common in PC, associated with lower hospice use and a potentially mutable source of racial/ethnic disparity in end-of-life care. **Abstract (inc. link to references):** <http://bit.ly/2HrKtav>

### **Assisted (or facilitated) death**

Representative sample of recent journal articles:

- *HASTINGS INTERNATIONAL & COMPARATIVE LAW REVIEW* | Online – Accessed 23 April 2019 – ‘**Legislating the right-to-die with dignity in a Confucian society: Taiwan’s Patient Right to Autonomy Act.**’ In Confucian societies, people tend to avoid the discussion on death matters, let alone making advance directives to reject life-sustaining treatments at the end of life (EoL). Taiwan might be a pioneer in legislating the right-to-die with dignity among Confucian countries. As early as 2000, the Hospice Palliative Care Act was declared in Taiwan, which give terminally-ill patients the options to forgo life-sustaining treatments. Furthermore, in 2016, Taiwan passed the Patient Right to

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Autonomy Act to enhance patients' choice at the EoL and expanded the coverage to certain types of non-terminally ill patients. On the other hand, EoL issues in Japan are regulated mainly through courts' judgments and medical societies' guidelines. Korea passed a law to legalize passive euthanasia, which became effective in 2018, but only contains limits to terminally-ill patients. The author analyzes the socio-cultural emphasis on family unity in East Asia and attitudes toward death in East Asian cultures, and then the methods adopted in Japan and South Korea of solving related disputes through the judiciary or legislation are explained. The author goes on to describe the legislative background of the aforementioned two laws in Taiwan, including futile medical care, the denial of citizen autonomy with respect to serious injury and death by criminal law theory, the unwillingness of the judiciary to intervene, and disputes encountered at medical sites. Subsequently, the author explains the primary content of these two laws, including patients' rights to self-determination, the judgment procedures of medical institutions, and the operation of advance directives. Finally, this article analyzes inadequacies in the Patient Right to Autonomy Act, including a lack of penalties, insufficiencies in medical institutions' scope of duty of disclosure, and the lack of a settlement mechanism for individuals who have not yet established advance directives. **Abstract:** <http://bit.ly/2L66ONA>

**N.B.** To view full text, click on



Noted in Media Watch 17 October 2016 (#483, p.16):

- *THEORETICAL MEDICINE & BIOETHICS* | Online – 5 October 2016 – ‘**Death with dignity from the Confucian perspective.**’ The authors attempt to reconstruct Confucian views on human dignity and the dignity of death and, based on those views, to analyze the following issues: the relationship between the dignity of death and biological life, the relationship between the dignity of death and suffering, the relationship between the dignity of death and the autonomy of human beings, and the relationship between the dignity of death and social justice. This article also compares the Confucian views on these issues with the views of Western philosophers. Confucian ethics can offer distinct answers to the above issues and help resolve some confusions concerning concepts and theories in Western research on the dignity of death. **Abstract (w. list of references):** <http://bit.ly/2DrXUDG>

## Publishing Matters

### The problem of predatory journals

*AAMC NEWS* | Online – Accessed 21 April 2019 – Roughly 12 times a day, Kurt Albertine, PhD, deletes emails from suspicious journals inviting him to submit articles. The invitations are from predatory journals: Publications that charge authors steep fees for publishing, use deceptive solicitation tactics, and sidestep or shortcut the peer-review process. Some of the emails are obviously bogus – Albertine, editor-in-chief of *The Anatomical Record*, says they occasionally bear the grammatical errors of phishing scams – but others are more convincing. One of Albertine's colleagues, a renowned and well-published physician at the University of Utah School of Medicine, where Albertine is a pediatrics professor, recently shared his fear that he had inadvertently submitted a manuscript to a predatory journal. The frightening lesson: If an experienced professor can fall prey, anyone can. “It's getting harder to distinguish a legitimate journal from a predatory journal that isn't peer reviewed,” says Ross McKinney, MD, AAMC chief scientific officer. “They have professional looking websites and people on their editorial board who look legitimate.” Yet in some cases, members are assigned to editorial boards without their consent, and authors frequently learn about fees – which can range from \$1,000 to \$10,000 – only after their paper has been accepted. The International Committee of Medical Journal Editors published an editorial on the issue in 2017.<sup>1</sup> It damningly described the problem: “These journals accept and publish almost all submissions, are not transparent about article processing (or publication) fees, often mimic the names and formats of legitimate journals to mislead authors and readers, and may collect fees but never publish the accepted work. In short, they subvert the peer-review publication system for the sole purpose of making money.” What's more, concerns are only growing. The association of American Medical College's *Academic Medicine* published an article on the topic in December 2018,<sup>2</sup> noting “the explosion in the number of predatory journals and publishers that deceive and prey on naive academic authors.” **Full text:** <http://bit.ly/2GyXHAR>



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1. “Fake,” “predatory,” and “pseudo” journals: Charlatans threatening trust in science,’ International Committee of Medical Journal Editors, 2017. **Full text:** <http://bit.ly/2VkJDxSU>
2. ‘Open access medical journals: Promise, perils, and pitfalls,’ *Academic Medicine*, published online 18 December 2018 (noted in 31 December 2018 issue of Media Watch (#595, p.24). **Abstract (click on pdf icon to access full text):** <http://bit.ly/2Xu4FfH>

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