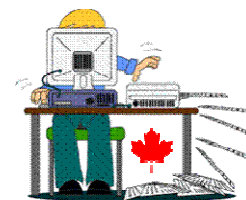


Media Watch...

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

Oncology nurses play a central role in “brokering” the introduction of early palliative care; this process is supported by their relational proximity to patients and their location “in between” the patient and the oncologist.

“‘I’m going to push this door open. You can close it.’”: A qualitative study of the brokering work of oncology clinic nurses in introducing early palliative care’ (p.17), in *Palliative Medicine*.

Canada

A (lack-of) action plan for palliative care in Canada

CANADIAN HEALTHCARE NETWORK | Online – 23 October 2019 – In August 2019, the federal government released its “action plan” for palliative care (PC) in Canada.¹ Action is necessary. In their own 2018 predecessor document, “Framework on Palliative Care in Canada,” the government admits that while 75% of Canadians would rather die at home, only 15% have access to the necessary community-based services.² This is generalizable to Ontario, where Institute of Clinical Evaluative Sciences (ICES) confirms that only one in five patients receives a home visit from a physician in their last year of life, and that only 50% of Ontarians receive PC services, with the majority of that care taking place in a hospital.³ This is despite the fact that ICES has also reported that community-based PC reduces ER use and hospitalizations, decreases aggressive medical interventions and provides better quality care when compared with usual care. In some cases, patients even live longer when they receive high-quality PC. ICES also demonstrates that community-based PC decreases hospitalizations and acute care hospital use, such as ER visits. A report from the Canadian Society of Palliative Care Physicians shows that inpatient PC services can save approximately \$7,000 to \$8,000 per hospitalization and reduce hospital costs by 24%.⁴ To quote Boston surgeon Dr. Atul Gawande: “If PC was a drug, we would patent it.” Yet in Ontario ... residential hospices must fundraise more than 50% of their operating expenses just to keep their doors open and the lights on. Imagine if this was the case for any other medical specialty. Would anyone stand for this in obstetrics, oncology, surgery or primary care? Unfortunately, this federal action plan will not make a demonstrable difference to patients at the bedside or in their homes. More reports and more nibbling around the edges will not make a difference in our patients’ care. <http://bit.ly/2Pp0JMs>

1. ‘Action Plan on Palliative Care,’ Health Canada, August 2019. **Download/view at:** <http://bit.ly/2Jno3Xa>
2. ‘Framework on Palliative Care in Canada,’ Health Canada, December 2018. [Noted in 10 December 2018 issue of Media Watch (#593, p.1)] **Download/view at:** <http://bit.ly/2AVEghF>

Cont.

3. 'Palliative care delivery across health sectors: A population-level observational study,' *Palliative Medicine*, published online 16 June 2016. [Noted in 20 June 2016 issue of Media Watch (#467, p.15)] **Full text:** <http://bit.ly/31NjzQ8>

N.B. The embedded link to ICES is, in fact, to 'Palliative & End-of-Life Care Provincial Roundtable Report: A Report from Parliamentary Assistant John Fraser to the Minister of Health & Long-Term Care,' March 2016. [Noted in 14 March 2016 issue of Media Watch (#453, p.1)] **Download/view at:** <http://bit.ly/32OE9Ru>

4. 'How to improve palliative care in Canada: A call to action for federal, provincial, territorial, regional and local decision makers,' Canadian Society of Palliative Care Physicians, November 2016. [Noted in 7 November 2016 issue of Media Watch (#486, p.2)] **Download/view at:** <http://bit.ly/2NjQvKy>

Noted in Media Watch 24 September 2018 (#582, p.1):

- *THE GLOBE & MAIL* | Online – 19 September 2018 – '**Almost all Canadians would benefit from palliative care. Only one in seven can actually access it at end-of-life.**' An estimated 89% of Canadians could benefit from palliative care (PC) in the last year of life. But only 15% are actually getting it. That's a pretty damning commentary on the state of end-of-life care in this country, and it only tells part of the story. The new data reveals that even those who get PC tend to get it late, and that far too many dying patients are shuffled around mercilessly between home, hospitals and nursing homes in their final days.¹ <https://tgam.ca/2kpgzTv>

1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. **Download/view at:** <http://bit.ly/2MqmCYO>

U.S.A.

Advance care planning may not reduce healthcare use

MEDPAGE | Online – 1 November 2019 – Advance care planning (ACP) is increasingly considered a crucial component of quality end-of-life-care – and one that may lower healthcare costs by avoiding aggressive interventions that patients don't want. But a large cohort study of seriously ill Medicare Advantage beneficiaries suggests that for those nearing the end of life, ACP may not be associated with a reduction in healthcare use. Researchers from the University of Pennsylvania's Perelman School of Medicine in Philadelphia report that billed ACP encounters are more frequently associated with hospitalization, hospice care, and death, though they are less frequently associated with intensive therapies, such as chemotherapy. The researchers analyzed a cohort of 18,484 seriously ill Medicare Advantage patients whose mean age was 79.7 years (54.3% women). From October 2106 through November 2017, 864 beneficiaries had a billed ACP visit, and 17,620 beneficiaries had no billed ACP visit. The researchers found that an ACP claim was associated with: 1) A higher

likelihood of hospice enrollment in the 6 months after the index ACP visit; 2) Higher mortality in the 6 months after the index ACP visit; 3) A greater likelihood of hospitalization; 4) A greater likelihood of admission to the intensive care unit; and, 5) A lesser likelihood of receiving any intensive therapies and especially chemotherapy. <https://wb.md/36wozMH>

Extract from *MedPage* article

According to an invited commentary, end-of-life ACP is being increasingly recommended on the assumption that if patients are informed about options, many will choose less aggressive care than they would otherwise receive. Driving the urgency of these conversations is the concern that much of the care that is currently provided toward the end of life may be overly aggressive and thus misaligned with patients' values.

1. 'Placing value on end-of life care – is it time for a new taxonomy,' *JAMA Network Open*, published online 1 November 2019. **Full text:** <http://bit.ly/2qaEf7A>

1. 'Advance care planning claims and healthcare utilization among seriously ill patients near the end of life,' *JAMA Network Open*, published online 1 November 2019. **Full text:** <http://bit.ly/33a9NJk>

Cont.

Related

- **MEDPAGE** | Online – 27 October 2019 – ‘**Many cancer patients receive questionable end-of-life treatments.**’ Patients with terminal cancer are not recommended to receive intensive medical services at the end of life (EoL), but more than half are receiving these services...¹ In the last year of life, patients experience a disproportionate share of medical spending. Although much of this spending is associated with the costs of serious illness, clinicians can often predict when costly intensive medical services have low value for patients at the EoL. Spending on intensive medical services at the EoL can have an adverse financial impact on patients and their families... Intensive services at the EoL are not linked to better outcomes, are associated with poorer patient quality of life, and are considered undesirable by many patients. <http://bit.ly/32WeFkY>

1. ‘Health system and beneficiary costs associated with intensive end-of-life medical service,’ *JAMA Network Open*, published online 27 September 2019. **Full text:** <http://bit.ly/32UvfSI>

End-of-life care laws were supposed to help New Yorkers. They don’t always work

STATE OF NEW YORK | *ProPublica* – 31 October 2019 – A decade ago ... New York enacted a series of laws meant to improve how people died. The legislation had two major components: First, healthcare providers treating the terminally ill are now required to offer to inform patients or those lawfully entitled to make decisions for them of the full range of options for navigating their final days, including the right to “comprehensive pain management” and the right to decline any or all care. Second, under the Family Health Care Decisions Act of 2010, families were empowered to make choices about care for an incapacitated loved one, including to end life-sustaining treatment if certain conditions are met. The legislation, dealing with people who did not have a designated healthcare proxy or a set of what are known as advanced directives,

created a hierarchy of who got to make those decisions – a spouse or child or legal guardian, even what the law listed as a “good friend.” Ten years on, though, there are many who worry that the legislation has had less of an impact than hoped. <http://bit.ly/2BYUhnK>

Specialist Publications

‘**Colorado End-of-Life Options Act: A clash of organizational and individual conscience**’ (p.19), in *Journal of the American Medical Association*.

‘**Medical aid in dying, hastened death and suicide: A qualitative study of hospice professionals’ experiences from Washington State**’ (p.19), in *Journal of Pain & Symptom Management*.

Hospice’s biggest fans now have second thoughts

TENNESSEE | WPLN News (Nashville Public Radio) – 29 October 2019 – The booming hospice industry is changing what it looks like to die in the U.S. Rather than under the care of doctors and nurses in a hospital, more Americans than not now spend their final days in familiar surroundings, often at home, being cared for by loved ones. While hospice has been a beautiful experience during a difficult time for many families, a year-long reporting project by WPLN finds end-of-life support often falls short of what they need. “Our long-term care system in this country is really using family, unpaid family members. That’s our situation,” says professor Katherine Ornstein, who studies the last year of life at Mount Sinai Hospital in New York.¹ “As we increasingly see that we want to provide home-based care, we’re relying even more on caregivers. And it does take a toll.” The federal government has found that families often misunderstand what they’re entitled to when they elect hospice. And many still have to pay out of pocket for nursing home services or private caregivers, which Medicare rarely covers – all while the hospice agency is paid nearly \$200 a day. Hospice has catapulted from a sector led by non-profits and volunteers to one dominated by investor-owned companies ... with more growth expected. In the process, hospice has ballooned into a nearly \$19 billion industry. It’s now the most profitable service sector in healthcare, as the industry’s business model relies heavily on unpaid family caregivers. <http://bit.ly/31Yn9GY>

1. ‘Spousal caregivers are caregiving alone in the last years of life,’ *Health Affairs*, 2019;38(6):964-972. [Noted in 10 June 2019 issue of *Media Watch* (#617, p.6)] **Full text:** <http://bit.ly/2IICPwc>

Cont.

Related

- TENNESSEE | WPLN News (Nashville Public Radio) – 30 October 2019 – ‘**Hospice industry’s most profitable patients get the least help.**’ The problem is that hospice wasn’t designed for dementia patients, even though they now represent the largest cost to Medicare. And according to the Medicare Payment Advisory Commission, the only reason the average length of hospice stay increases each year is because patients with diseases like dementia are choosing to start hospice even earlier. But the government benefit was established in 1983 with cancer patients in mind and primarily focuses on relieving pain. So hospice agencies don’t have to provide the kind of caregiving that people with dementia really need. <http://bit.ly/36f6q5E>

As homeless Washingtonians near the end of life, hospice workers offer comfort wherever needed

STATE OF WASHINGTON | *Crosscut* – 29 October 2019 – With more than half of the nation’s homeless population over the age of 50, access to hospice care is a dire need. Without permanent housing, health issues are exacerbated, new illnesses develop and access to regular medical care is more difficult. Those experiencing homelessness are dying much sooner, from their 40s to early 50s, compared with an average life span of 78 for the population as a whole, according to a study from the University of Tennessee Health Science Center.¹ Washington’s homeless population currently ranks as the fifth highest in the country, and looking at King County in 2018, over one-third of the deaths (73 of 194) of homeless people resulted from natural causes. Emergency rooms, frequently the first stop in the healthcare system for the homeless, often will make the necessary hospice referrals. But where do they send someone without housing? In 2018, Joshua’s House opened in Sacramento, California, breaking ground as the first hospice care facility for the homeless on the West Coast and one of only a handful across the country. Washington has no such dedicated inpatient facility, but some organizations across the state are doing work to make the last months of the state’s homeless residents more comfortable and less lonely. And while there are no state laws or regulations that ensure someone in hospice gets housing, there are a number of ways that hospice is provided to some people living in, or having recently moved out of, homelessness. <http://bit.ly/2BXGc9P>

1. ‘Care of the homeless: An overview,’ *American Family Physician*, 2014;89(8):634-640. **Full text:** <http://bit.ly/34h2l9X>

N.B. Selected articles on end-of-life care for the homeless in the U.S. noted in 7 January 2019 issue of *Media Watch* (#596, p.3).

The special challenges of nearly 11 million seniors who live in rural communities

FORBES | Online – 28 October 2019 – When we think about older adults in the U.S., we usually focus on those living in cities or suburbs. By doing so, we forget about the rural elderly, who represent an outsize share of people living in these communities and who have very special challenges. According to a new report by the U.S. Census bureau, about 10.6 million older adults live in rural communities – roughly one quarter of all seniors.¹ But they represent a much larger fraction of their local populations than urban seniors. About 17.5% of rural residents are over 65, while only about 14% of urban residents are older adults. Three-quarters of rural older adults live in the South and Midwest,

but in states such as Maine and Vermont almost two-thirds of seniors live in rural communities. And the more rural the area, the older it likely is. Census found that about 20% of the residents of what it calls “completely rural” communities are 65 or older. <http://bit.ly/36gn05f>

Extract from *Forbes* article

In many rural areas, there are no Medicare- or Medicaid-certified home care agencies or hospice programs. Thus, providers must travel many miles to deliver care, if it is available at all.

1. ‘The Older Population in Rural America: 2012-2016 American Community Survey Reports,’ U.S. Census Bureau, September 2019. **Download/view at:** <http://bit.ly/32YKbPn>

Cont.

N.B. Selected articles on the provision and delivery of hospice and palliative care services in rural America noted in 7 October 2019 issue of Media Watch (#634, p.2).

House [of Representatives] approves hospice education act

HOSPICE NEWS | Online – 28 October 2019 – The U.S. House of Representatives has passed the Palliative Care & Hospice Education & Training Act (PCHETA) ... The bill ... had 294 bipartisan co-sponsors. If enacted, PCHETA would establish fellowship programs within new palliative care (PC) and hospice education centers to provide short-term, intensive training on PC and hospice. The courses would provide supplemental training for medical school faculty as well as other educators in healthcare fields such as nursing, pharmacy, social work and chaplaincy. The centers would also develop curricula related to PC and support continuing education, retraining of faculty, practical clinical training and establish training programs for advanced practice nurses. The bill will next go to the Senate where it currently has 33 co-sponsors. <http://bit.ly/31UO86j>

Noted in Media Watch 23 September 2019 (#632, p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 16 September 2019 – ‘**Future-proofing the palliative care workforce: Why wait for the future?**’ Careful consideration of workforce issues is not new in palliative care (PC). Indeed, calls for workforce development and future workforce planning to address shortages have been evident within the international literature for quite some time. However, there now appears to be a growing urgency. Studies conducted by the American Academy of Hospice & Palliative Medicine’s Workforce Task Force have pointed towards an impending crises in the form of a “workforce valley” associated with factors such as burnout, intention to leave PC, retirement age demographics, and limitations in specialist training.¹ **First page view:** <http://bit.ly/2krYIC9>

1. ‘Policy changes key to promoting sustainability and growth of the specialty palliative care workforce,’ *Health Affairs*, 2019;38(6):910-918. [Noted in 10 June 2019 issue of Media Watch (#617, p.1)] **Full text:** <http://bit.ly/2QMAU7N>

Noted in Media Watch 5 February 2018 (#549, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 February 2018 – ‘**The growing demand for hospice and palliative medicine physicians: Will the supply keep up?**’ The current U.S. supply of hospice and palliative medicine (HPM) specialists is 13.35 per 100,000 adults 65 and over. The authors project need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. Current training capacity is insufficient to keep up with population growth and demand for services. HPM fellowships would need to grow from the current 325 graduates annually to between 500 to 600 per year by 2030 to assure sufficient physician workforce for hospice and palliative care services given current service provision patterns. **Full text:** <http://bit.ly/2CRjxwO>

Noted in Media Watch 29 January 2018 (#548, pp.9-10):

- *HEALTH ECONOMICS, POLICY & LAW* | Online – 23 January 2018 – ‘**Projecting shortages and surpluses of doctors and nurses in the Organisation for Economic Co-operation & Development: What looms ahead.**’ The authors work develops a projection model for the demand of doctors and nurses by Organisation for Economic Co-operation & Development (OECD) countries in the year 2030. The model is based on a country’s demand for health services, which includes the following factors: per capita income, out-of-pocket health expenditures, and the ageing of its population. The authors project a shortage of nearly 400,000 doctors across 32 OECD countries and shortage of nearly 2.5 million nurses across 23 OECD countries in 2030. The **Abstract:** <http://bit.ly/2JvdTns>

International

Stop futile treatment, even if patient’s relatives insist, Israeli doctors say

ISRAEL | *Haaretz* (Tel Aviv) – 1 November 2019 – Doctors must stop giving treatments that don’t help their patients, even if their families insist, the Israel Medical Association says in a paper addressing the treatment of terminal patients. The paper tells doctors not to attempt resuscitation attempts or administer other treatments if they are known to be futile in advance. When the medical solutions prove ineffective, doctors should move on to supportive or palliative care, it says. Resuscitation attempts or tests and treatments that won’t help the patient or prolong his life could be redundant and even harmful. “The futile treatment infringes on the patient’s right to put his affairs in order while he is still capable of doing so,” the paper says. The paper says doctors frequently administer treatment they know is futile for non-medical reasons, such as compassion or difficulty to give the bad news to the patient’s family. The paper says there is no justification for carrying out resuscitation when the doctor knows it won’t help or prolong the patient’s life and in some conditions could even be seen as harmful. <http://bit.ly/2NwuY1v>

Aged care system “cruel and harmful” and underfunded, say inquiry commissioners

AUSTRALIA | *The Guardian* (Sydney, New South Wales) – 31 October 2019 – Australia’s aged care system is “cruel and harmful” with services that are fragmented, unsupported, underfunded and often unsafe and uncaring, according to the findings of the aged care royal commission’s interim report.¹ The commission has called for an urgent overhaul of the sector, saying it is neglecting the needs of Australia’s older, vulnerable citizens and is “unkind and uncaring.” Outlining a litany of problems in the sector fuelled by a culture of ageism, the commissioners ... have described the aged care system in Australia as “a shocking tale of neglect.” “The neglect that we have found in this Royal Commission, to date, is far from the best that can be done. Rather, it is a sad and shocking system that diminishes Australia as a nation,” a statement from the commissioners says. On the need for home care packages, the commission report says the system is “unfair,” with funding needed to allow people to live safely at home. The report also highlights concerns about the country’s “ageist” mindset, saying this culture had led to an indifference to how older people were treated, with the conversation about aged care too often about burden, encumbrance and obligation. Slamming the system as fragmented, unsupported and underfunded, and usually poorly managed, the report says that many residential aged care homes are also unsafe and “seemingly uncaring.” <http://bit.ly/2WsBfiQ>

1. ‘Interim Report of the Royal Commission into Aged Care, Quality & Safety,’ October 2019. **Download /view at:** <http://bit.ly/31YlakV>



Royal Commission into Aged Care Quality and Safety

Extract from the Commission’s Interim Report

People suffering from a terminal illness, or nearing the end of their life’s span, may need palliative care (PC) while they are in residential care. For some people, their whole experience of residential aged care is in palliation, or in dying. This may last a few months. For others, the time in palliation and end-stage care is at the end of a number of years in the residential facility. We have heard that the availability and standard of PC provided in residential aged care is widely variable... Residential aged care is a place where people will and do die, and that experience should be as free from pain and fear as possible for the person.

Specialist Publications

‘Australian GPs’ perceptions of barriers and enablers to best practice palliative care: A qualitative study’ (p.9), in *BMC Palliative Care*.

‘Doctors’ perspectives on adhering to advance care directives when making medical decisions for patients: An Australian interview study’ (p.13), in *BMJ Open*.

‘Providing palliative care closer to home: A retrospective analysis from a remote Australian hospital’ (p.9), in *Internal Medicine Journal*.

Study finds caregiving can affect quality of life for up to a year after loss

AUSTRALIA (Western Australia) | *Have a Go News* (Perth) – 29 October 2019 – Family members who have been the primary carer for a dying loved one may experience considerable grief and poor health and quality of life (QoL) for several months after the person has died, new research led by Curtin University has found.¹ The research ... aimed to determine whether family carers' grief, general health and QoL worsened following a loved one's death, compared to non-carers. It also examined whether the grief a carer experienced while caring could predict their grief following the death. Lead author Associate Professor Lauren Breen, from the School of Psychology at Curtin University, said family carers are integral to providing end-of-life care for people receiving palliative care, but the tasks of caregiving can have a significant and lasting impact on them. "Caring for a dying loved one can be a full-time and exhaustive commitment, but the grief, general health and QoL that the carer experiences before and after death can sometimes be overlooked," Associate Professor Breen said. "By measuring how carers were feel-

ing in the time period leading up to the death, and then at three different time periods following the death, we were able to show that it took nine to 10 months for the carers' grief, general health, and QoL to return to 'normal.' We also found that while caring, the carers' QoL and general health was low and their grief was similar to what they experienced three to four months following the death." The findings highlighted the need for services to provide adequate support for carers. <http://bit.ly/2PxleFB>

Specialist Publications

'The experiences of family caregivers at the end of life: Suffering, compassion satisfaction and support of healthcare professionals' (p.15), in *Journal of Hospice & Palliative Nursing*.

'Informal caregivers in cancer: Roles, burden, and support' (p.15), in PDQ Cancer Information Summaries.

1. 'Effect of caregiving at end of life on grief, quality of life, and general health: a prospective, longitudinal, comparative study,' *Palliative Medicine*, published online 29 October 2019. **Full text:** <http://bit.ly/2q1wcK6>

New palliative care policy on the anvil

INDIA (Kerala) | *The Hindu* (Thiruvananthapuram) – 29 October 2019 – After 11 years since Kerala announced its palliative care (PC) policy, it is taking a fresh look at the document. A new and revised policy, which addresses some of the yawning gaps in the current policy, is expected to be released soon. An expert committee ... has already submitted the final draft to the government. Once approved by the government, an implementation framework and an action plan will be drawn up before any changes on ground can be expected. "In the West, PC services are readily available at the tertiary care level. In Kerala, it is exactly the opposite. PC services have been flourishing at the primary care level, while little or no services are available at the tertiary care level," said M.R. Rajagopal, chairperson, Pallium India. In Thiruvananthapuram and Kozhikode, two districts where PC first took roots in Kerala, the services are still run by non-governmental organisations (NGOs). At the institution-level, medical colleges do not have a PC division, with the result that medical students, including postgraduates, have no exposure to palliation and pain management. Ensuring effective PC services at the tertiary care hospitals and starting departments of palliative medicine in medical colleges are the major recommendations in the revised policy. The revised policy recommends networking of some 300 NGOs involved in delivering PC in the State and creating a PC grid, akin to the National Cancer Grid, so that there is better integration of services, knowledge-sharing and quality improvement initiatives. <http://bit.ly/2PwfGfQ>



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Hong Kong homes for elderly “need major upgrades” to provide support for terminally ill patients ahead of proposed law change for end-of-life care

CHINA (Hong Kong) | *South China Morning Post* – 13 October 2019 – The Food & Health Bureau launched a three-month consultation in September on proposed legislation to improve end-of-life care in Hong Kong. The proposals include giving patients a choice of where to spend their final days, if they prefer not to die in hospital. To allow the terminally ill to die in elderly care homes, the government has suggested amending the Coroners Ordinance to exempt homes from having to report a death to the Coroner if the resident was seen by a doctor during the preceding 14 days. About 62,000 people live in 747 elderly care homes, according to official figures. More than 73% of the homes are private facilities, most of which do not receive government subsidies. Even if the proposed laws are passed, homes ... have to overcome a number of obstacles before they can give residents the choice of “dying in place” instead of being sent to hospital. This is because the homes will have to take special care when they provide hospice services and start dealing with deaths on their premises. <http://bit.ly/2BMblx9>

Specialist Publications

“Farewell” to prognosis in shared decision-making

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 30 October 2019 – Whether because of a cultural pattern or personal preference, palliative care clinicians encounter persons approaching the end of life (EoL) who wish to limit or forego prognostic information relating to their situation. The ordinary expectation for EoL shared decision-making with a capable person is clinician disclosure of the best effort at prognostic assessment. The optimal match between the expressed values, goals, and preferences of the person with available clinician expertise is hopefully achieved. For the clinician, a person’s choice to modify information disclosure and participation in shared decision-making represents a significant challenge of balancing key ethical principles of intervention with tolerance and compassion for these different preferences. Attention to communication strategies that elicit and appropriately reassess individual information and decision-making wishes, flexibility in information disclosure patterns with capable persons and their representatives, and recognition that a respect for autonomy includes the choice to opt out can approach this challenge while providing compassionate and ethical EoL care. **Abstract:** <http://bit.ly/2Nv06P5>

Dying in acute hospitals: Voices of bereaved relatives

BMC PALLIATIVE CARE | Online 31 – October 2019 – Internationally there is an increasing concern about the quality of end-of-life care (EoLC) provided in acute hospitals. More people are cared for at end of life and die in acute hospitals than in any other healthcare setting.

The majority of survey respondents (87%) rated the quality of care as outstanding, excellent or good during the last admission to hospital. The quality of care by nurses, doctors and other staff was highly rated. Overall, care needs were well met; however, findings identified areas of care which could be improved, including communication and the provision of emotional and spiritual support. In addition, relatives strongly endorsed the provision of EoLC in single occupancy rooms, the availability of family rooms on acute hospital wards and the provision of bereavement support. This research provides a powerful snapshot in time into what works well and what could be improved in EoLC in acute hospitals. Findings are reported under several themes, including the overall quality of care, meeting care needs, communication, the hospital environment and support for relatives. Results indicate that improvements can be made that build on existing good practice that will enhance the experience of care for dying persons and their relatives. The study adds insights in relation to relative’s priorities for EoLC in acute hospitals and can advance care providers’, policy makers’ and educationalists’ priorities for service improvement. **Full text:** <http://bit.ly/324C42G>



**HospiceFriendly
HOSPITALS**



N.B. Hospice Friendly Hospitals, Irish Hospice Foundation, website: <http://bit.ly/2NRbQLy>

Australian GPs' perceptions of barriers and enablers to best practice palliative care: A qualitative study

BMC PALLIATIVE CARE | Online – 31 October 2019 – GPs [i.e., study participants] reported difficulties with palliative care (PC) provision due to: 1) The complex and often emotional nature of doctor-family-interaction; 2) A lack of evidence to guide care; and 3) The need to negotiate roles and responsibilities within the healthcare team. GPs listed a number of strategies to help deal with their workload and to improve communication processes between healthcare providers. These included appropriate scheduling of appointments, locally tailored mentoring and further education, and PC guidelines which more clearly outline the roles and responsibilities within multidisciplinary teams. GPs also noted the importance of online platforms to facilitate their communication with patients, their families and other healthcare providers, and to provide centralised access to locally tailored information on palliative care services. GPs suggested that non-government organisations could play an important role by raising awareness of the key role of GPs in PC provision and implementing an “official visitor” program, i.e., supporting volunteers to provide peer support or respite to people with PC needs and their families. This study offers new insights into strategies to overcome well documented barriers to PC provision in general practice and help implement optimal care at the end of life. **Full text:** <http://bit.ly/2r3L4br>

Related

- *INTERNAL MEDICINE JOURNAL* | Online – 29 October 2019 – ‘**Providing palliative care closer to home: A retro-spective analysis from a remote Australian hospital.**’ Rural and remote patients have reduced access to palliative care (PC), often resulting in interhospital transfers and death a long way from home and family. Katherine Hospital, Northern Territory, a 50-bed hospital services a population with high Aboriginality who experience this issue. The number of deaths in Katherine Hospital increased from 23 in 2011 to 52 in 2018. During the same period, the proportion of all deaths classified as palliative increased from 51.4% to 66.0%, with fewer deaths occurring in the emergency department. The number of aero-medical transfers of patients from Katherine Hospital to tertiary centres decreased from 769 in 2011 to 434 in 2018. Increasing the capacity of a remote hospital to provide PC allowed more patients to die closer to home and decreased inappropriate aero-medical retrievals. **Abstract:** <http://bit.ly/2C3l2Go>

N.B. Additional articles on the provision and delivery of palliative and end-of-life care in rural and remote regions of Australia noted in 23 September 2019 issue of Media Watch (#632, p.15).

Palliative care training addressed to hospital healthcare professionals by palliative care specialists: A mixed-method evaluation

BMC PALLIATIVE CARE | Online – 26 October 2019 – Despite the great advances in the concept of palliative care (PC) and its benefits, its application seems to be delayed, leaving unfulfilled the many needs of patients and family members. One way to overcome this difficulty could be to develop a new training programme by PC specialists to improve PC primary skills in healthcare professionals. The aim of this study was to evaluate the training's impact on trainees within a hospital setting using Kirkpatrick's and Moore's models. The results of this study [conducted at the General Hospital Arcispedale Santa Maria Nuova, a 900-bed public hospital, located in Reggio Emilia, Italy] highlighted the significant amount of knowledge acquired by the hospital professionals after training, in terms of increasing their knowledge of PC and in terms of the change in meaning that they attributed to phenomena related to chronicity and incurability, which they encounter daily in their professional practice. In both quantitative and qualitative research, the results, in synthesis, highlight: 1) The development of a new concept of PC, centred on the response to the holistic needs of people; 2) That PC can also be extended to non-oncological patients in advanced illness stages (our training was directed to Geriatrics and Nephrology/Dialysis professionals); 3) The empowerment and the increase in self-esteem that healthcare professionals gained, from learning about the logistical and structural organization of PC, to activate and implement PC; 4) The need to share personal aspects of their professional life (this result emerges only in qualitative research); and, 5) The appreciation of cooperation and the joining of multiple competences towards a synergistic approach and enhanced outcomes. **Full ext:** <http://bit.ly/36cevbv>

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Related

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 24 October 2019 – ‘**Elements of palliative care in the last 6 months of life: Frequency, predictors, and timing.**’ Persons living with serious illness often need skilled symptom management, communication, and spiritual support. Palliative care (PC) addresses these needs and may be delivered by either specialists or clinicians trained in other fields. The authors identified receipt and timing of core elements of PC... Although a high proportion of patients received elements of PC, transitions to a goal of comfort or hospice happened very near death. PC delivery can be improved by systematizing existing mechanisms, including prompts for earlier goals-of-care discussion, symptom screening, and spiritual care, and by building collaboration between primary and specialty PC services. **Abstract (w. list of references):** <http://bit.ly/2BMfUj4>

Access to paediatric palliative care in children and adolescents with complex chronic conditions: A retrospective hospital-based study in Brussels, Belgium

BMJ: PAEDIATRICS OPEN | Online – 29 September 2019 – Paediatric palliative care (PC) for children/adolescents in Belgium is provided through five paediatric liaison teams (PLTs), each of which is attached to a university hospital. The mission per centre is to ensure continuity of care through all care settings (in and out of hospital) for children with life-limiting or life-threatening conditions, including complex chronic condition. Funding of these PLTs has been integrated into the Belgian Health coverage since 2010. In 2016, the legislation was modified to state that PC should not be restricted to end-of-life care but should be provided progressively according to patients’ needs and wishes, independently of life expectancy. Even though it is the mission of the two PLTs [that cover the eight hospitals in the Brussels region] to ensure continuity of care between the hospital and the homes of children with a serious illness, the authors found that only a very small percentage of the 22,533 children with a chronic complex disease who were identified over a 5-year period admitted to a hospital were followed up by one of the city’s two PLTs. The results of their study suggest that the number of referrals of such children and adolescents to a PLT in Belgium is probably insufficient or is reserved for the most complex situations. Further studies are needed to estimate the type of care needed by children and adolescents facing complex chronic conditions but also to better understand why those patients are insufficiently referred to paediatric liaison teams. **Full text:** <http://bit.ly/367u9Vm>



Noted in Media Watch 28 May 2018 (#565, p.9):

- *BMC PALLIATIVE CARE* | Online – 22 May 2018 – ‘**Building bridges, paediatric palliative care in Belgium: A secondary data analysis of annual paediatric liaison team reports from 2010 to 2014.**’ A Royal Decree issued in 2010 provides the legal framework that defines the paediatric liaison teams’ mission as ensuring continuity of curative and palliative care between the hospital and home for children diagnosed with life-limiting conditions. This national study describes how these teams ensure continuity of care by describing their activities and the characteristics of the children they cared for... **Full text:** <http://bit.ly/2Pr27yb>



[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>

Culturally responsive supports for Métis elders and Métis family caregivers

CANADIAN JOURNAL ON AGING | Online – Accessed 28 October 2019 – Cultural responsiveness is necessary to ensure that care provided to both Métis Elders/seniors and Métis family caregivers meets their needs. It is essential that the Canadian population, especially policy and decision makers, recognize that legitimate challenges remain with the resources available to understand what the current experiences and health of Métis people are presently like. This challenge is being addressed by the Métis Nation and its citizens. While the larger constitutional and legal battles take place in the courts as to legal identity, land rights, and fiduciary responsibilities, the smaller battles are waged at home as people work to ensure that their loved one can live at home as long as possible, that there are language supports in place that allow Elders to communicate in their language, and that family caregivers also have support to meet their ongoing economic, social, and pragmatic needs. The Métis population is growing. Increased rates of self-identification related to an increased sense of safety ... and pride associated with Métis identity, changes to

census data collection procedures ... as well as higher fertility rates are largely responsible for this change in demographics... It is important that continued exploration of the needs of family caregivers and the Elders they support are undertaken while keeping culture as part of the discussion. This will not only allow for continued recognition of the influence colonial practices and policies have had, but also ensure that the well-being of Indigenous people is at the forefront of policy and service delivery which in turn will improve the lives of Métis citizens across the lifespan. **Full text:** <http://bit.ly/2BS6DOI>

Canadian Journal on Aging / La Revue canadienne du vieillissement

Special Issue on Aging in Indigenous Populations

Journal contents page: <http://bit.ly/2BOv4vZ>

N.B. Selected articles on palliative and end-of-life care for the Indigenous peoples of Canada noted in 24 June 2019 and 3 September 2018 issues of Media Watch (#619, p.6 and #579, p.12, respectively.)

Palliative and hospice care in correctional facilities: Integrating a family nursing approach to address relational barriers

CANCER NURSING | Online – 21 October 2019 – The need for palliative and hospice care for persons with life-limiting conditions who are incarcerated is increasingly common in correctional facilities worldwide. Through a family nursing lens, the authors critically analyze the unique challenges experienced by those requiring palliative care while incarcerated. Key concerns and implications for nursing are illustrated through the discussion of a representative case scenario. By applying a family nursing approach, nurses practicing with correctional populations can ensure persons with life-limiting illnesses are not denied their right to appropriate end-of-life care by playing a key role in addressing barriers to palliative and hospice care access in corrections. Specific attention to relational issues and holistic care can contribute to enhanced palliative and hospice care, greater dignity in dying, and improved family and peer outcomes, which have benefits for individuals, families, communities, and society. The authors illustrate real issues emerging in correctional contexts and offer evidence of how family nursing relational principles can be applied to promote adequate palliative and hospice care. **Abstract:** <http://bit.ly/2Jz6BiG>



UNIVERSITY OF SASKATCHEWAN

Centre for Forensic Behavioural Science and Justice Studies

N.B. A compilation of selected articles, etc., on end-of-life care in the prison system noted in past issues of Media Watch can be downloaded/viewed from/at the Palliative Care Network website: <http://bit.ly/2RdegnL>

“If only...”: Counterfactual thinking in bereavement

DEATH STUDIES | Online – 25 October 2019 – When grief over the death of a loved one becomes complicated, protracted and circular, ruminative counterfactual thinking in which the bereaved relentlessly but vainly seeks to somehow reverse the tragedy of the loss often plays a contributory role in sustaining the person’s suffering. In this article, the authors summarize the growing evidence implicating this cognitive process in interfering with meaning reconstruction following loss, and identify four foci for counterfactual, “if only” cognition, directed at the self, the deceased, relevant others, or the circumstances of the death itself. They then illustrate each with an actual case vignette, along with approaches to resolving, dissolving, mitigating, or redirecting such rumination, and conclude with a general principle of practice for other therapists whose clients struggle with similarly anguished and entrenched counterfactual preoccupations.

Abstract: <http://bit.ly/2BNPgy3>

End-of-life communication needs for adolescents and young adults with cancer: Recommendations for research and practice

JOURNAL OF ADOLESCENT & YOUNG ADULT ONCOLOGY | Online – 29 October 2019 – A growing evidence base highlights the negative impact of poor psychosocial care at end-of-life (EoL). Adolescents and young adults (AYAs) ... with cancer face unique medical and psychosocial challenges that make them especially vulnerable when treatment is not successful. Although the importance of age-appropriate medical and psychosocial care is internationally recognized for AYAs across the cancer trajectory, there is little guidance on best-practice care and communication practices with AYAs as they approach the EoL. Research undertaken to date emphasizes the importance of exploring AYAs’ preferences around EoL issues in a repeated, consistent manner, and highlighted that AYAs may have strong preferences on a range of issues such as being able to stay in their own home, being comfortable and free from pain, and expressing their wishes to loved ones. The authors highlight a number of best-practice recommendations to guide clinicians around the critical elements of when, who, what, and how EoL conversations may be best facilitated with AYAs. They propose a new model to support clinicians and researchers to better conceptualize how interacting individual, familial, and socio-cultural factors impact EoL communication with AYAs in clinical settings. **Abstract:** <http://bit.ly/2q2Weg8>

Noted in Media Watch 24 June 2019 (#619, p.11):

- *PEDIATRIC BLOOD & CANCER* | Online – 17 June 2019 – ‘**Things that matter: Adolescent and young adult patients’ priorities during cancer care.**’ Study participants’ frequent priorities were cure (97%), being good to the people they care about (95%), and having supportive people around them (94%). Most prioritized being with family (90%), returning to school/work (89%), maintaining relationships with friends (88%), and feeling normal (85%). Fewer prioritized minimizing long-term (78%) and acute side effects (68%) and fertility (59%). Many participants (88%) said that cure influenced their decisions “a great deal,” while fewer were influenced by side effects (32%), fertility (36%), or relationships (16%). Most patients (85%) thought their oncologist understood what was most important to them when treatment started. **Abstract:** <http://bit.ly/2KWqstz>

Noted in Media Watch 10 June 2019 (#617, p.8):

- *JOURNAL OF CLINICAL ETHICS*, 2019;30(2):131-142. ‘**Physicians’ perspectives on adolescent and young adult advance care planning: The fallacy of informed decision making.**’ This study identified two categories important to the utility of advance care planning (ACP) in pediatric hematopoietic stem cell transplant (HSCT) patients: 1) The temporal context of ACP and decision making; and, 2) The limitations of pediatric ACP, with sub-categories identified as a) embodied and witnessed knowing, b) the impact of clinical cascades ... and a creation of a “new normal” following complications of illness and its treatment in the pediatric intensive care unit; c) The balancing of adolescents’ autonomy with their capacity to make informed medical decisions; and, d) The epistemological frames that differ between healthcare professionals and patients and their families. **Abstract:** <http://bit.ly/2FpPSLx>

N.B. See ‘Crossroads of Grief Project – Grieving or Bereaved Children: Literature Review,’ (pp.9-10, ‘End-of-Life Care in Children and Adolescents’), Children & Youth Grief Network of Peel Region (Ontario, Canada), May 2019. **Download/view at:** <http://bit.ly/2QZBaAs>

Advance care planning conversations in the oncology setting: Tips from the experts

JOURNAL OF CANCER EDUCATION | Online – 26 October 2019 – Advance care planning (ACP) has been identified as a fundamental part of every patient's total healthcare plan and is actively supported by a number of healthcare organizations. Despite these endorsements, however, having ACP conversations has not come easily for physicians. Training future physicians should include practical ways to address this issue. Fifty physicians at an oncology hospital, who were identified as having the most ACP conversations, were approached. Major themes were noted and summarized for each of a survey's 10 questions, resulting in how the physicians can successfully plan for and initiate ACP conversations with their patients and families. Themes touched upon self-awareness, one's outlook on the value of life, and the importance of death as part of the care continuum. A physician's own perception of the value of ACP conversations greatly influences them having those conversations. Furthermore, it is key that the physician understands and be aware of the patient's perspective regarding their cancer and how it impacts them. This dynamic will then allow the physician to better align their plan of care with the treatment goals and expectations of the patient. Future training programs should incorporate these suggestions. **Abstract (w. list of references):** <http://bit.ly/36cxna8>

Related

- *BMJ OPEN* | Online – 31 October 2019 – '**Doctors' perspectives on adhering to advance care directives when making medical decisions for patients: An Australian interview study.**' Advance care directives (ACDs) provide doctors with opportunities to align patient preferences with treatment and uphold patient autonomy. However, they experience conflict ... especially when they believe that adhering to the ACD is not in the patients' best interests, or if they doubt the validity of the ACD. Future advance care planning (ACP) programmes should consider approaches to improve the validity and applicability of ACDs. In addition, there is a need for ethical and legal education to support doctors' knowledge and confidence in ACP and enacting ACDs. **Abstract:** <http://bit.ly/2PzCAmB>
- *JOURNAL OF APPLIED GERONTOLOGY* | Online – 28 October 2019 – '**Going it alone: Advance directive discordance in older married couples.**' Contrary to expectations of joint decision-making, a substantial minority of older married couples report only one spouse possessing an advance directive (AD). It was predicted that spouses who differed in age, self-rated health, or race/ethnicity would be more apt to adopt individualistic as opposed to relational motivational stances, resulting in higher odds of non-matching AD status. Study results raise concerns about the effectiveness and reach of advance care planning promotion efforts among low-education and non-White older married adults. **Abstract:** <http://bit.ly/2JEi5l1>

Integrating the Comfort Theory™ into pediatric primary palliative care to improve access to care

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(5): 382-389. Primary palliative care (PC) improves access to symptom control and quality-of-life care (QoLC) for children and families and can reduce moral distress in clinicians. This article describes the application of a nursing theory framework for an evidence-based practice/quality improvement project that embedded pediatric primary PC into a hospital-based setting using unit-specific projects. An evidence-based practice/quality improvement project, guided by the Comfort Theory™, provided primary PC education and mentorship to improve knowledge, skills, and attitudes of direct care clinicians. Training consisted of didactic and self-directed learning, mentoring, and completion of unit-based projects to establish meaning and impact best practices and policies. A total of 149 direct care clinicians, comprising 3 cohorts, enrolled in the program. Improvements in interdisciplinary collaboration in care were demonstrated through 21 unit-based projects, the development of triggers for specialty PC consults in several high-risk populations, and the development of institutional guidelines for QoLC. The Comfort Theory™ guided integration of PC for children with serious illness and their families. This project empowered direct care clinicians in caring for patients, providing support to clinical staff, and in developing best practices. **Abstract:** <http://bit.ly/2JrVS9B>



Guiding the process of dying: The personal impact on nurses

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(5):390-396. Some of the most ethically challenging and emotionally demanding aspects of nursing occur in caring for patients and their family at the end of life (EoL). The aims of this study were to examine the views of acute care nurses caring for patients during transition to comfort care, to describe the personal impact on nurses, and to identify nurses' strategies for self-support and development of competence. Nurses [i.e., study participants] experienced moral distress in situations of continuing treatment when a cure was unlikely. In managing symptoms for patients, they struggled to foster an often-tenuous balance of patient comfort and calm without over-sedation. They struggled to manage the competing demands of a workload including patients receiving curative care juxtaposed with those focused on comfort care. Nurses reflected on their fears as new nurses caring for EoL patients, the inadequacy of their preparation for this role, and their distress when the care provided felt inadequate to them. Nurses navigated challenges through support from nurse colleagues and effective leaders. They appealed to administrators to attend to care concerns arising from time-intensive nature of care. Mentoring and education facilitated assimilation to comfort-care nursing for novice nurses. **Abstract:** <http://bit.ly/2JoGIlo>

Noted in Media Watch 14 October 2019 (#635, pp.3-4):

- *Critical Care Nurse*, 2019;39(5):38-49. '**Palliative care and moral distress: An institutional survey of critical care nurses.**' Fewer than 40% of survey respondents reported being highly competent in any palliative care (PC) domain. Most respondents had little PC education, with 38% reporting none in the past 2 years. Most respondents reported moral distress during the study period, and moral distress levels differed significantly on the basis of perceived use of PC. Respondents who perceived less frequent use of PC tended to experience higher levels of moral distress. **Abstract:** <http://bit.ly/2MRVhQL>

Work satisfaction among hospice and palliative nurses

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(5):E1-E11. This article reports the results of a nationwide survey of 633 hospice and palliative nurses [in the U.S.] evaluating job satisfaction, intent to leave, job stressors, suggested work improvements, and self-care strategies. Statistically significant correlations were found between the Home Healthcare Job Satisfaction Scale and subscales and the individual's self-rating of overall job satisfaction, likelihood of leaving the job, and thoughts of quitting. Multiple regression revealed a significant positive association between salary and overall job satisfaction, relationship with the organization, professional pride, autonomy, and control. A grounded theory approach was utilized to analyze qualitative data. Top job stressors identified were workload and problems with administration. Physical activities were cited as the most popular for self-care. Results indicate that most participants were highly satisfied with their work, but almost half think of quitting some or all of the time, indicating dissatisfaction with the work environment. Respondents suggested that employers increase recognition and salary, create a more positive work environment, decrease workload, and focus on patient needs rather than profits. **Abstract:** <http://bit.ly/2BPpIWE>

Related

- *CANADIAN JOURNAL OF NURSING RESEARCH* | Online – 23 October 2019 – '**Self-perceived competence of nurses and care aides providing a palliative approach in home, hospital, and residential care settings: A cross-sectional survey.**' This study explored the extent to which nurses' and care aides' self-perceived palliative care (PC) competence may explain variation in the application of a palliative approach across nursing care settings that do not specialize in PC. In addition to self-perceived competence, factors associated with a palliative approach include identification of patients who have life-limiting conditions and who would benefit from a palliative approach, and work environment. **Abstract:** <http://bit.ly/2q0UaVX>



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

End-of-life travel: A bucket list desire for patients with life-limiting illnesses

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(5):397-403. Patients at end of life (EoL) often express a desire to travel, and many have requests that go unfulfilled. Studies show that a majority of patients have a desire to return to their place of birth to die when presented with the option, yet goals-of-care (GoC) conversations do not routinely include travel desires for numerous reasons. Patients faced with a life-limiting illness are at greater risk of depression, withdrawal, denial, anger, and feelings of helplessness. When palliative care (PC) teams assist patients with EoL travel, they empower them with a greater sense of control over the dying process. Improving GoC conversations regarding medical travel begins with well-developed communication skills and a knowledge of available options. This article primarily focuses on the recommendation of medical travel as a GoC comfort measure for the PC patient.

Abstract: <http://bit.ly/36btngz>

Noted in Media Watch 18 June 2018 (#568, p.12):

- *QUALITY OF LIFE RESEARCH* | Online – 12 June 2018 – ‘**Exploring the lived experience of migrants dying away from their country of origin.**’ This study aimed to explore the lived experience of migrants dying away from their country of birth or origin. Three notions emerged. The first was dual possession of a new hybrid identity developed in their adoptive country, and an inner ethnic and cultural identity, in varying degrees of harmony with each other. The second was being in life review – re-living homeland memories and letting go of dreams. The third notion showed how they sought resolution by enacting continuity through their children, hoping for a final homeland visit, or conveying their dying wishes. **Abstract (w. list of references):** <http://bit.ly/347HqM0>

N.B. Selected articles on repatriation to their homeland of patients living with a terminal illness noted in 28 November 2016 issue of Media Watch (#489, pp.15-16).

The experiences of family caregivers at the end of life: Suffering, compassion satisfaction and support of healthcare professionals

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(5):438-444. A death with dignity is influenced by the quality of care offered to patients. The objective of this study was to identify, through the firsthand experiences and insights of family caregivers, the key elements related to the care offered to patients with a terminal illness at the end of life (EoL). This multicenter qualitative study was based on the paradigm of hermeneutic phenomenology. Participants were relatives of patients with terminal illness who had been identified as primary caregivers. Five discussion groups and 41 in-depth interviews were organized with a total of 81 participants. The results indicate the existence of three dimensions: 1) The caregiver’s suffering; 2) Compassion satisfaction with the care provided; and, 3) The support of healthcare professionals. Understanding the experiences of family members providing EoL care allows improved care and provides dignity in death. Health and social systems must provide comprehensive assistance covering the different aspects of needed care.

Health professionals occupy a privileged position in the care of these patients and their families.

Abstract: <http://bit.ly/36aERKQ>

Informal caregivers in cancer: Roles, burden, and support

PDQ CANCER INFORMATION SUMMARIES | Online – 23 October 2019 – This summary for health professionals provides comprehensive, peer-reviewed, evidence-based information about challenges and helpful interventions for caregivers of cancer patients. 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 healthcare decisions. This summary is reviewed regularly and updated as necessary by the PDQ Supportive and 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:** <http://bit.ly/2qX2OFm>

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Noted in Media Watch 21 October 2019 (#636, p.17):

- *REVISTA LATINO-AMERICANA DE ENFERMAGEM* | Online – 14 October 2019 – ‘**Uncertainty in illness in family caregivers of palliative care patients and associated factors.**’ The results of this study show that high levels of uncertainty in illness are associated, in a slight but significant way, with the condition of the patient who is cared for and the symptoms presented by him, the length of service as a caregiver, and the support that the caregiver perceives coming from health professionals, family and religion. These findings provide evidence on the importance of the nursing professional in identifying the needs and assisting the family caregiver of the patient in palliative care; the strengthening of the family support network of this patient-caregiver dyad; and, the need to recognize the value of religious or spiritual support groups. **Full text:** <http://bit.ly/2px1Tuk>

N.B. To access the *Revista Latino-Americana de Enfermagem* article click on pdf icons to access the full texts in either English, Portuguese or Spanish. Selected articles on the role and the importance of the family caregiver as a member of the palliative care team noted in the September issue of the newsletter of the International Association for Hospice & Palliative Care: <http://bit.ly/2IJANOL>

Early palliative care in chronic obstructive pulmonary disease

JOURNAL OF PALLIATIVE MEDICINE | Online – 29 October 2019 – Guidelines recommend that pulmonary clinicians involve palliative care (PC) in chronic obstructive pulmonary disease (COPD); however, integration before advanced stage, that is, early PC, is rare. Pulmonary and PC clinicians [i.e., study participants] agreed that early PC could add value to disease-focused COPD care. Perspectives on many barriers and facilitators were shared between specialties along broad educational, clinical, and operational categories. Pulmonary and PC clinicians shared concerns about the misconception that PC was synonymous to end-of-life care. Pulmonologists were particularly concerned about the potential risks of opioids and benzodiazepines in COPD. Both specialties stressed the need for clearly defined roles, consensus referral criteria, and novel delivery models. Although no single referral criterion was discussed by all, frequent hospitalizations and emotional symptoms were raised by most across disciplines. Multi-morbidity and poor prognosis were discussed only by PC clinicians, whereas medication adherence was discussed only by pulmonary clinicians. Pulmonary and PC clinicians supported early PC in COPD. Continued needs include addressing pulmonologists’ misconceptions of PC, establishing consensus referral criteria, and implementing novel early PC models. **Abstract:** <http://bit.ly/36cebti>

Noted in Media Watch 30 September 2019 (#633, p.10):

- *MEDICINE* | Online – 16 September 2019 – ‘**Psychosocial interventions for patients with severe chronic obstructive pulmonary disease: An up-to-date literature review.**’ 34 studies were identified and divided into four thematic groups: 1) Home medical support 2) Exercise; 3) Self-management; and, 4) Mental health. The number of studies that focused on mental health preservation in severe chronic obstructive pulmonary disease COPD is limited. Improving patients’ self-efficacy gave promising effects to the acceptance of palliative care, pulmonary rehabilitation completion and mental health. Psychosocial interventions applied in advanced COPD underline the roles of self-efficacy, telehealth and physical activity in physical and mental health preservation. **Abstract:** <http://bit.ly/2krTwOE>

N.B. Additional articles on PC for people living with COPD noted in 5 August 2019 issue of Media Watch (#625, pp.7-8).

Interventions to reduce aggressive care at end of life among patients with cancer: A systematic review

LANCET ONCOLOGY, 2019;20(11):PE627-PE636. Little is known about effective interventions to reduce aggressive end-of-life (EoL) care in patients with cancer. Of the 6,451 studies identified by the authors’ five randomized control trials and 31 observational studies met the final inclusion criteria. Sixteen sub-categories of interventions were identified. With the exception of documentation of EoL discussions in the electronic medical record, no single intervention type ... led to consistent improvements in aggressive

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EoL care measures. The ability to discern the interventions' effectiveness was limited by inconsistent use of validated measures of aggressive care. Seven (23%) of 31 observational studies and no randomized control trials were at low risk of bias according to Cochrane's Risk of Bias tool. Evidence for improving aggressive EoL cancer care is limited by the absence of standardised measurements and poor study design. Policies and studies to address the gaps present in EoL care for cancer are necessary. **Abstract (w. list of references):** <http://bit.ly/2qbtL7M>

Dying of amyotrophic lateral sclerosis: Health care use and cost in the last year of life

NEUROLOGY | Online – 31 October 2019 – In this large population-based cohort of decedents, individuals with amyotrophic lateral sclerosis (ALS) spent more days in the ICU, received more community-based services, and incurred higher costs of care in the last year of life. A palliative care physician home visit was associated with improved end-of-life outcomes; however, the majority of patients with ALS did not access such services. **Abstract:** <http://bit.ly/34nRBMn>

N.B. Additional articles on PC for people living with ALS noted in 10 June 2019 issue of Media Watch (#617, p.12).

“I’m going to push this door open. You can close it.”: A qualitative study of the brokering work of oncology clinic nurses in introducing early palliative care

PALLIATIVE MEDICINE | Online – 29 October 2019 – The role of nurses in facilitating the early involvement of palliative care (PC) is unclear. The core category, brokering PC, represented the overarching concept of this study that linked other sub-categories: 1) Opening the door – creating the possibility of discussing early PC at a time when patients show signs of being receptive to this discussion; 2) Building trust – establishing relationships with patients as a starting point for open discussions about PC; 3) Tackling misconceptions – addressing patients' assumptions about PC as signifying death; and, 4) Advocating with oncologists – seeding the process of referral by bringing patients' concerns forward. Oncology nurses play a central role in “brokering” the introduction of early PC; this process is supported by their relational proximity to patients and their location “in between” the patient and the oncologist. Training all nurses in PC and empowering them to have proactive discussions in a collaborative practice context would allow greater access to early PC. **Abstract:** <http://bit.ly/2MYect7>

Population-based quality indicators for end-of-life cancer care: A systematic review

JAMA ONCOLOGY | Online – 24 October 2019 – Are population-based quality indicators for the care of patients with cancer who have advanced disease and/or are at the end of life (EoL) appropriate for use? In this systematic review, 288 quality indicators (260 unique), extracted from 35 references to 28 individual studies, for the care of patients with cancer who had advanced disease and/or who were at the EoL were identified, of which 27.8% were appropriate for use, 40.3% were inappropriate for use, and 31.9% were of limited testing. Acceptability and validity had the fewest positive assessments; benchmarking data were reported for only 16 quality indicators. The findings suggest that only a small proportion of quality indicators developed for the care of patients with cancer who have advanced disease and/or are at the EoL have received adequate testing and/or are appropriate for use. **Abstract:** <http://bit.ly/367QAK1>

The effectiveness of aromatherapy, massage and reflexology in people with palliative care needs: A systematic review

PALLIATIVE MEDICINE | Online – 29 October 2019 – Aromatherapy, massage and reflexology are widely used in palliative care (PC). Despite this, there are questions about their suitability for inclusion in clinical guidelines. The need to understand their benefits is a public priority, especially in light of funding pressures. Twenty-two trials, involving 1,956 participants were identified. Compared with a control, four eva-

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luated aromatherapy, eight massage and six reflexology. A further four evaluated massage compared with aromatherapy. Trials were at an unclear risk of bias. Many had small samples. Heterogeneity prevented meta-analysis. In comparison with usual care, another therapy or an active control, evidence on the effectiveness of massage and aromatherapy in reducing anxiety, pain and improving quality-of-life was inconclusive. There was some evidence (low quality) that compared to an active control, reflexology reduced pain. This review identified a relatively large number of trials, but with poor and heterogeneous evidence. New clinical recommendations cannot be made based on current evidence. To help provide more definitive trial findings, it may be useful first to understand more about the best way to measure the effectiveness of these therapies in PC. **Abstract:** <http://bit.ly/2BPTNzV>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMJ OPEN* | Online – 30 October 2019 – ‘**Australian pharmacists’ perspectives on physician-assisted suicide: Thematic analysis of semi-structured interviews.**’ This study has investigated the perspective of Australian pharmacists regarding their role in physician-assisted suicide (PAS) and found the need for a sound ethical and legal framework to support PAS, as well as the need for training and budgetary considerations. These findings provide a platform to help shape future policies for the successful implementation of PAS in healthcare. Some of the findings have implications for clinical educators in developing new guidelines and policy-makers in formulating policies that detail the role of pharmacists in PAS. We recommend that these views and strategies be considered, and an inclusive approach be adopted for all stakeholders involved in this process. **Full text:** <http://bit.ly/34cxq3Y>
- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 November 2019 – ‘**Medical assistance in dying: Research directions.**’ Euthanasia and assisted suicide, both sometimes referred to as medical assistance in dying (MAiD), have in recent years become increasingly important concerns for public health and for end-of-life (EoL) care. In a context of increased life expectancy, protracting illness trajectories before death and changing discourses around patient autonomy, dignity and “good death,” an increasing number of jurisdictions have legalised forms of MAiD, that is, acts in which the death of a seriously ill and suffering person is hastened by means of a lethal dose of drugs at this person’s request. Up until a decade ago, the number of jurisdictions that legally accepted some form of MAiD was limited to a handful of relatively small European countries ... and one state in the U.S... In the last decade (ie, between 2009 and 2018), this was substantially expanded with three countries (Luxembourg, Colombia and Canada) and eight states (Washington, Vermont, Montana, California, Colorado, Hawaii and Washington DC in the U.S. and the Australian state of Victoria). This means that over 180 million people now live in a place where they can legally access MAiD. This increased public health relevance of MAiD also intensifies its importance within EoL care research. Up until now, research has particularly been limited to the early-adaptation countries and states and, even there, a number of concerns regarding MAiD practice have not yet been studied adequately. From the authors’ impression of the current state of research regarding MAiD practices, a number of shortcomings and needs in research can be identified. **Introductory paragraphs:** <http://bit.ly/36ruJ0d>
- *CRISIS* | Online – 28 October 2019 – ‘**Grief after euthanasia and physician-assisted suicide: A systematic review.**’ Several countries have regulated euthanasia and physician-assisted suicide (PAS). Research has looked at the experiences of patients, family, and professionals. However, little is known of the effects on bereaved individuals. A literature search identified 10 articles (eight studies), and the study quality was fair. People bereaved by euthanasia/PAS generally had similar or lower scores on measures of disordered grief, mental health, and posttraumatic stress compared with those who died naturally. Lack of social support and secrecy may compound their grief. Being involved in the decision-making process and having the feeling of honoring the deceased’s will may facilitate their grief. There is little evidence of increased risk of adverse grief or mental health outcomes in people bereaved by euthanasia/PAS. As more countries legalize assisted dying, high-quality studies of the factors that may hinder or facilitate the grief process are needed. **Abstract:** <http://bit.ly/32YuXK9>

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Would this article be of interest to a colleague?

Noted in Media Watch 11 March 2019 (#605, p.15):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 1 March 2019 – ‘**Impact of medical assistance in dying (MAiD) on family caregivers.**’ The aim of this article is to explore the experience of medical assistance in dying (MAiD) from the family caregiver perspective, namely their beliefs and opinions about the intervention, how the process of MAiD impacts them, how the intervention shapes their view of their loved one’s quality of death, and the psychosocial outcomes after the passing of their loved one. Beyond the literature, challenges within both the clinical and research realms are discussed and future directions are offered. **Abstract:** <http://bit.ly/2NFkviY>
 - *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION* | Online – 29 October 2019 – ‘**Colorado End-of-Life Options Act: A clash of organizational and individual conscience.**’ The 2016 Colorado End-of-Life Options Act includes a provision unique among states with such laws, specifically privileging individual healthcare professionals, including physicians and pharmacists, to choose whether to write and fill prescriptions for life-ending medications, such as high-dose secobarbital or various combinations of morphine, diazepam, beta-blockers, and digoxin, without regard to the position their employer has taken on the law. This provision virtually guaranteed the Colorado law would eventually be challenged, which happened in August 2019. The current legal case directly pits the conscience rights of individual healthcare professionals against those of religiously affiliated corporations. Because 5 of the top 10 U.S. hospital systems by net revenue are now religiously affiliated, and these systems often restrict medical care in a variety of ways, how the case is resolved could have far-reaching implications for U.S. healthcare, extending well beyond the relatively rare use of aid-in-dying medications at the end of life. **Abstract:** <http://bit.ly/2BYwFij>
- N.B.** Commentary on Colorado End-of-Life Options Act article: <http://bit.ly/2Jxm5nn>
- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 1 October 2019 – ‘**Medical aid in dying, hastened death and suicide: A qualitative study of hospice professionals’ experiences from Washington State.**’ Many jurisdictions around the world have passed medical aid in dying laws allowing competent, eligible individuals facing life-limiting illness to self-administer prescribed medication to control timing of death. These laws do not prevent some patients who are receiving hospice services from dying by suicide without assistance. Three primary themes were identified from the interviews: 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 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 legalised 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:** <http://bit.ly/2PIyoAP>

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