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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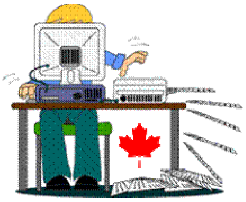

Compiled & Annotated by Barry R. Ashpole

One of the biggest obstacles to initiating a timely palliative approach is clinicians' inability to reliably identify people who could benefit from it.

'Early identification of people who would benefit from a palliative approach: Moving from surprise to routine' (p.11), in *JAMA Network Open.*

Canada

New palliative care program provides end-of-life support for Victorians living in poverty

BRITISH COLUMBIA | CFAX 1070 Radio (Victoria) – 19 September 2019 – Death may be the great equalizer, but for people who are destitute getting access to quality end-of-life care (EoLC) may leave them feeling far from equal. To bridge that gap, a new mobile palliative care (PC) program, Palliative Outreach Resource Team (PORT), is providing care and dignity to people with life-limiting illnesses who are living in poverty in Victoria. PORT is a pilot program that connects people with serious illnesses with caregivers, PC and other health and social support systems. The program is built upon lessons learned from a three year study led by University of Victoria PC researcher Kelli Stajduhar.[1] The study followed 25 people who were homeless or barely housed while struggling with life-threatening medical conditions. The 2018 report found that homeless and barely housed people faced many barriers when seeking EoLC. For people who are dying and living in poverty, the ability to access services – such as healthcare – decline as their health declines. In contrast, the study found those who were able to access PC actually experienced an improvement to their quality of life. http://bit.ly/2m3vrOQ

Specialist Publications

'Gaps in public preparedness to be a substitute decision-maker and the acceptability of high school education on resuscitation and end-of-life care: A mixed-methods study' (p.9), in *CMAJ Open.*

'A feasibility study of home-based palliative care telemedicine in rural Nova Scotia, Canada' (p.12), in *Journal of Palliative Medicine.*

1. 'Too little, too late: How we fail vulnerable Canadians as they die and what to do about it,' Institute on Aging & Lifelong Health, November 2018. [Noted in 5 November 2018 issue of Media Watch (#588, p.1)] **Download/view at:** http://bit.ly/2Ilg47D

N.B. Additional articles on palliative and end-of-life care for the homeless in Canada noted in 5 November 2018 issue of Media Watch (#588, p.1).

Court rules McGill University Health Centre can change treatment plan for dying patient

QUEBEC | CBC News (Montreal) – 18 September 2019 – A Quebec Superior Court judge has granted the McGill University Health Centre (MUHC) the right to proceed with end-of-life care (EoLC) in the case of a 74-year-old woman, despite opposition from her family. The woman has been in intensive care at the Royal Victoria Hospital since the end of July and has no hope for recovery. The MUHC had asked the court to rule if it should stop providing treatment and respiratory support to the woman, and replace the current treatment plan with palliative and comfort measures. The woman has Stage 4 Hodgkin's lymphoma that cannot be treated. She has also suffered from acute kidney and liver dysfunction, and has had multiple organ failures in addition to several other ailments. She is also currently on a ventilator and is unconscious and unable to communicate. In his submission to the court, the woman's physician, Dr. Gordan Samoukovic, said she is essentially dead and is being kept alive by artificial means. The hospital and the woman's family agree she is incapable of giving, or refusing, consent to change her treatment. But they differ on whether to change her treatment plan to palliative care (PC). The ruling notes that MUHC and the woman's family recognize she is unable to give or refuse her consent to a change to PC. But the woman's husband and one of her sons categorically refuse any change to bring about EoLC. Another son testified he is in favour of the change in treatment proposed by the MUHC and he believes his mother would also consent if she could. http://bit.ly/2kpjAdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NOVA SCOTIA | Global TV News (Halifax) – 18 September 2019 – **'Nova Scotia Health Authority quietly changes medically-assisted dying policy at Catholic hospital.'** Under the threat of a possible court challenge, Nova Scotia has quietly changed its policy on medically-assisted dying at a Catholic hospital in the province. In a statement to Global News, the Nova Scotia Health Authority says: "Assessments and provision of MAiD [medical assistance in dying] will be available in a section of St. Martha's Regional Hospital complex at the Antigonish Health & Wellness Centre." St. Martha's Regional Hospital was exempt from assisted dying services as the result of a 1996 agreement between the Nova Scotia government and the Sisters of St. Martha that gave control of the hospital to the Nova Scotia government. http://bit.ly/2kut6vQ

  Noted in Media Watch 14 January 2019 (#597, p.1):

  - NOVA SCOTIA | Global TV News (Halifax) – 9 January 2019 – **'St. Martha's Hospital remains firm on policy against medically-assisted dying.'** The Sisters of St. Martha has an agreement with the Nova Scotia government forbidding medical assistance in dying at St. Martha's Hospital in Antigonish. Almost three years after the federal government legalized medically-assisted dying, critics say it's time for the Saint Martha's exemption to end. "The bottom line is that a faith-based institution should not be allowed to impose its' faith, its values, on the citizens of a community who may not share them," said Jocelyn Downie, a professor at the Schulich School of Law at Dalhousie University… More than 100 Catholic hospitals and nursing homes across Canada also forbid medically-assisted dying, including 17 sites operated by Covenant Health in Alberta. http://bit.ly/2mr9Sb4

MY CARE My Right.

whpca
worldwide hospice palliative care alliance

World Hospice & Palliative Care Day 12 October 2019

The theme 'My Care, My Right' aims to communicate that palliative care (PC) can be demanded by the public – and that, together, every person impacted by a life limiting illness can influence their policy makers to prioritize PC financing under universal health coverage. http://bit.ly/2RMImQK

U.S.A.

Oregonians push to keep Hopewell House hospice open

OREGON | Oregon Public Broadcasting (Portland) – 20 September 2019 – Friends of Hopewell House have collected 1,400 signatures from people in favor of keeping it open. And they have $150,000 to put toward the cause. Legacy spokesman Brian Terrett said the company understands the concern, but fewer patients are choosing to die at Hopewell, opting instead for home hospice. The federal government's Centers for Medicare & Medicaid Services recently made it harder to be admitted for in-patient hospice care – patients have to be sicker now. Legacy thinks private insurance companies are likely to follow suit, meaning there will be even less demand for a place like Hopewell in the future. "This effort won't change the stricter criteria for being admitted as a general in-patient into Hopewell House, which is also impacting our numbers. It is important to point out that these are national trends happening all around the country," Terrett said. http://bit.ly/2mnrYul

Specialist Publications

'State legislation to prevent diversion of opioids in hospice programs: A deeper look into Ohio law' (p.12), in *Journal of Hospice & Palliative Nursing*.

'Education and end-of-life options: Hawaii's 'Our Care, Our Choice Act''(p.16), in *Hawaii Journal of Health & Social Welfare*.

Noted in Media Watch 2 September 2019 (#629, p.3):

- OREGON | *Portland Business Journal* – 28 August 2019 – **'Legacy plans to close house for hospice patients in Portland.'** Legacy Health is closing a hospice house in Southwest Portland, a reflection of trends in end-of-life care. As homey as Hopewell House is, the closure will allow Legacy to focus more on caring for the increasing numbers of patients who prefer to receive hospice services in their own homes... "We are finding that more and more people are choosing to receive hospice care in their own homes and thanks to technology, the level of care our hospice team can provide at home has increased significantly," Legacy Health spokesperson Kristin Whitney said. http://bit.ly/2MFHGgp

Noted in Media Watch 27 August 2018 (#578, p.3):

- MICHIGAN | MLive (Saginaw) – 20 August 2018 – **'Saginaw hospice care facility closing due to lack of patients.'** Cartwright Hospice Residence is closing because of the low number of residents admitted to the care facility. "We've really been evaluating this over multiple years," said Diane Glasgow, of the Covenant Visiting Nurse Association. "The amount of patients was decreasing year by year." Over the last few months they averaged about 1.8 residents a day and with a staff that included six full-time employees and part time employees it did not make it feasible. One reason numbers are low, she said, is because more people prefer to die at home instead of a facility. http://bit.ly/2lY8Cff

N.B. See 'Site of death, place of care, and health care transitions among U.S. Medicare beneficiaries, 2000-2015,' *Journal of the American Medical Association*, 2018;320(3):264-271. [Noted in 2 July 2018 issue of Media Watch (#570, p.4)] **Full text:** http://bit.ly/2m2p0LI

Why do patients deny their diagnoses?

FORBES | Online – 17 September 2019 – Of all the topics I wish was better taught when I was a medical student, learning how to recognize and address denial, is foremost among them. As physicians, we regularly encounter patients who, for one reason or another, simply don't fully accept their diagnoses. It's a cause of frustration for the patients, their family members, and treating clinicians. And yet, as common as denial is, it's also something we don't talk a lot about or acknowledge as part of the experience of illness. We often underestimate how hard it is for our patients to accept their diagnoses – and don't do enough to help them navigate their feelings. "Denial is one of the first stages of grief and loss," says Nina Perales, a

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behavioral health clinical educator at CareMore Health. Perales has spent a lot of time in exam rooms, helping patients cope with their diagnoses. She says that when patients receive a difficult diagnosis, they feel the same way people do when a close friend or relative dies. "Being told that you have an illness you never thought you'd get..." she says, "It's a grieving process." And the first step of grieving is often denial. What Perales is describing may, on the surface, seem like an unhealthy way to deal with difficult news, but denial is far more complicated than that. It is often the adaptive mechanism that allows patients to continue to live their lives in the face of information that might otherwise be paralyzing. The opposite of denial is acceptance. And accepting a diagnosis means accepting all the negative sequelae that are associated with a disease or condition. http://bit.ly/2knylgD

Florida guardians routinely issue "do not resuscitate" orders without court oversight

FLORIDA | ABC Action News – 16 September 2019 – Guardians across Florida have been routinely issuing "do not resuscitate" (DNR) orders on the people under their care with little oversight by the court system or transparency with the public... The shocking discovery comes after an investigative report in July accused professional guardian Rebecca Fierle of causing the death of a man under her care by issuing a DNR order and capping his feeding tube without permission. Fierle is under criminal investigation and a judge has ordered all DNRs removed on the nearly 100 people in her care in the Orlando area. A review of hundreds of court records, transcripts and hearings uncovered dozens of cases of guardians making life and death decisions for the people under their care. ABC Action News also discovered many of these decisions being made without oversight by the court system, which appoints guardians to care for those same people who have been deemed unable to care for themselves. It's unclear how many times guardians in Florida have issued DNRs because the orders often go unreported. http://bit.ly/2kSYfci

Noted in Media Watch 16 September 2019 (#631, p.6):

- *ELDER LAW JOURNAL*, 2019;27(1):1-34. **'Making end-of-life care decisions for older adults subject to guardianship.'** "Unbefriended" adults are those who lack decision-making capacity, have no advance directive, and have no family or friends to serve as a surrogate decision-maker. As such, professional guardians may be appointed when healthcare decisions are needed. Making healthcare decisions for such adults, particularly end-of-life care decisions, can be challenging. Little to nothing may be known about the person's values prior to guardianship and the patient may be unable to convey his or her wishes and goals to the guardian. **Abstract (via PubMed):** http://bit.ly/2K8LKlG

Noted in Media Watch 22 July 2019 (#623, p.3):

- FLORIDA | *The Orlando Sentinel* – 15 July 2019 – **'Man died after Orlando legal guardian filed "do not resuscitate" order against his wishes, investigation finds.'** A man died at a Tampa hospital after staff could not perform life-saving procedures because of a "do not resuscitate" order his Orlando guardian filed against his wishes, state investigators determined. The investigation into the final days of 75-year-old Steven Stryker of Cocoa caused Circuit Judge Janet C. Thorpe to seek the removal of his court-appointed guardian, Rebecca Fierle, from 98 Orange County cases at once in a hearing sealed from the media last week. http://bit.ly/2XPRIlj

Noted in Media Watch 22 July 2019 (#623, p.11):

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 13 July 2019 – **'End-of-life decision making and treatment for patients with professional guardians.'** Concerns have repeatedly been raised about end-of-life (EoL) decision making when a patient with diminished capacity is represented by a professional guardian (PG), a paid official appointed by a judge. Such guardians are said to choose high-intensity treatment even when it is unlikely to be beneficial or to leave pivotal decisions to the court. EoL decision making by PGs has not been examined systematically, however. **Abstract:** http://bit.ly/30yw6Xu

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International

More home care linked to shorter hospital stays

IRELAND | *Irish Health* (Dublin) – 18 September 2019 – Older patients who live in areas with more access to home care and residential care have shorter hospital stays, new research by the nm & Social Research Institute (ESRI) has found.[1] According to the findings, which focused on the period 2010 to 2015, there is a clear link between hospital stay duration and the supply of home and residential care. The researchers investigated whether patients over the age of 65, who lived in areas with better home care and residential care supply, were discharged more quickly from hospital. They found that when it came to home care, a 10% increase in supply *per capita* equated to around 14,7000 fewer inpatient days per year – that is the equivalent of 40 inpatient beds every day. Furthermore, the scale of this effect was much greater in those areas that had the largest supply of home care, especially when it came to patients with very long stays. Meanwhile, when it came to residential care, a 10% increase in supply *per capita* equated to around 19,000 fewer inpatient bed days per year – that is the equivalent of 53 inpatient beds every day. http://bit.ly/2kpzm7V

Extract from Economic & Social Research Institute report

For some groups such as those at the end of life, home-based palliative care has also been shown to reduce hospital use and reduce costs.

[1] 'An analysis of the effects on Irish hospital care of the supply of care inside and outside the hospital,' Economic & Social Research Institute, September 2019. **Download/view at:** http://bit.ly/2mrg7f7

U.S. attack on World Health Organization "hindering morphine drive in poor countries"

U.K. | *The Guardian* (London) – 18 September 2019 – An attack on the World Health Organization by U.S. politicians accusing it of being corrupted by drug companies is making it even more difficult to get morphine to millions of people dying in acute pain in poor countries... Representatives of the hospice and palliative care (PC) community said they were stunned by the Congress members' report, which they said made false accusations and would affect people suffering in countries where almost no opioids were available.[1] "At least 5 billion people live in countries where there is limited or no availability of opioids for pain treatment," according to the International Association for Hospice & Palliative Care (IAHCP). More than 18 million people a year worldwide die with "untreated, excruciating pain," the organisation says. The report by Democratic congresswoman Katherine Clark and Republican congressman Hal Rogers … has undermined efforts to encourage governments to buy generic morphine or other appropriate opioids and doctors to prescribe them, dealing a severe blow to the struggle to help people dying in acute pain from cancer, AIDS, injuries and other conditions, the IAHPC says.[2] The PC experts say low- and middle-income countries need cheap morphine, not patented opioid drugs such as OxyContin, at the centre of the U.S. opioids crisis. http://bit.ly/2kuKpgi

Specialist Publications

'£25 million for hospices won't go far' (p.8), in *British Medical Journal*.

'Impact of the Liverpool Care Pathway on quality end-of-care in residential care homes and home care: Nurses' perceptions' (p.13), in *Nursing Open*.

'Palliative care in primary care: European Forum for Primary Care position paper' (p.14), in *Primary Health Care Research & Development*.

'Psychosocial care provision for terminally ill clients in rural Australian communities: The role of social work' (p.15), in *Rural & Remote Health*.

[1] Link to the Congress' members report embedded in *The Guardian* article.

[2] 'IAHPC's response to a U.S. House of Representatives report and WHO's reaction to it,' International Association of Hospice & Palliative Care, July 2019. [Noted in 22 July 2019 issue of Media Watch (#623, p.4)] **Download/view at:** http://bit.ly/2NXciLZ

Caregivers of seriously ill spouses find life improves more when the partner dies

GERMANY | Reuters (Berlin) – 17 September 2019 – For caregivers tending to a seriously ill spouse, quality of life (QoL) may improve to a greater extent if the partner dies than if the partner recovers, a German study suggests.[1] That paradoxical finding – that life becomes more satisfying when sick partners die than when they recover – may arise from the fact that on average, bereaved caregivers in the study had heavier caregiving burdens, with sicker spouses and more hours spent caring for their loved one until the caregiver role ended... Caregivers whose partner recovered were largely unaffected in their life satisfaction, unless the burden in terms of weekday care, errands and housework hours or severity of spousal disease that was lifted off their shoulders was similarly high, in which case they also became similarly more satisfied with their lives upon recovery of their spouse... The study wasn't designed to prove whether or how caregiving for a partner or spouse impacts QoL or life satisfaction, or how this might shift with death or recovery of the patient. And results from Germany, where caregivers receive some financial support, may not reflect what would happen elsewhere in the world. Life satisfaction might be impacted differently by the caregiving burden in places where there isn't this type of financial support... https://reut.rs/2m3VIfy

1. 'After the burden is lifted: Caregivers' recovery of life satisfaction after the death or recovery of a spouse,' *Journals of Gerontology*, published online 10 September 2019. **Abstract:** http://bit.ly/2lUDjSG

Triaging the terminally ill

AUSTRALIA (Victoria) | *Health & Wellbeing* (University of Melbourne) – 16 September 2019 – The Responding to Urgency of Need in Palliative Care (RUN-PC) Triage Tool is expected to change practice internationally.[1] Demand for specialist palliative care (PC) is increasing because of our ageing population, but there are other factors. Earlier integration of PC in cancer care, enhanced involvement of PC in non-cancer diseases and increased community awareness and acceptance of PC are helping to drive demand. So, with a growing workload both in terms of the volume of referred patients and the diversity of those patients' needs, PC clinicians are facing difficult decisions on a daily basis as to how to allocate their clinical resources. All the patients are deserving, but which ones have urgent specialist PC needs and which ones can wait a little longer while they receive other hospital or community-based care? Until now, there has been very little research to develop a robust and fair system to triage PC needs, that is, to prioritise one person's needs over another. Today, there are simple, well tested and internationally-accepted tools to rate the severity of a patient's condition and allocate resources in a way that aims to help as many patients as possible. http://bit.ly/2mdEiNH

1. 'Development of the Responding to Urgency of Need in Palliative Care (RUN-PC) triage tool,' *Journal of Pain & Symptom Management*, published online 14 August 2019. [Noted in 19 August 2019 issue of Media Watch (#627, p.11)] **Abstract (w. link to references):** http://bit.ly/33HpwAm

Noted in Media Watch 9 July 2018 (#571, p.15):

- *PALLIATIVE MEDICINE*, 2018;32(7):1246-1254. **'Responding to urgency of need: Initial qualitative stage in the development of a triage tool for use in palliative care services.'** An evidence-based triage method to assess urgency of palliative care (PC) needs is required to ensure equitable, efficient and transparent allocation of specialist resources... A series of markers of urgency were identified in this study, including physical and psychological suffering, caregiver distress, discrepancy between care needs and care arrangements, mismatch between current site of care and desired site of death when in terminal phase and complex communication needs. **Abstract:** http://bit.ly/2kN062u

More need to consider healthcare directives

IRELAND | *Irish Health* (Dublin) – 16 September 2019 – More State supports are needed to encourage adults to put in place enduring powers of attorney and advance healthcare directives, Safeguarding Ireland has said. Safeguarding Ireland is a coalition of national organisations in the health, social and finan-

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cial sectors, that work together to protect vulnerable adults. Recent research commissioned by the coalition suggested that just 6% of adults have appointed an enduring power of attorney, while only 8% have discussed their preferred place of care. It is calling on the Government to introduce a State scheme in the forthcoming Budget to encourage more adults to put in place these important directives. It insisted that this would help to prevent and reduce the abuse of vulnerable adults, while also saving the State money in relation to social service costs. http://bit.ly/2lUdWQX

How dying prisoners are treated at HMP Dartmoor

U.K. (England) | Plymouth Live – 16 September 2019 – The healthcare team who provide dignified and compassionate end-of-life (EoL) care for prisoners at Her Majesty's Prisons Dartmoor have spoken about how they look after dying prisoners. Care UK's Health in Justice team recently won the top award in the EoL category in this year's *Health Service Journal* Patient Safety Awards.[1] The awards are among the most prestigious in healthcare and recognise the hard work and dedication of teams across the country to patients' care and safety. Natasha Head, head of healthcare at the prison, said: "I was amazed when the judges called our name. It is an award that has been made possible by lots of committed and compassionate people. Specialist nurses come into the prison to review the care for prisoners nearing the end of their lives. These prisoners would usually have to be escorted to a hospital outside the prison or be transferred away from the prison, which would not only cost taxpayers thousands of pounds but would also reduce access to the right care – and add another layer of stress to their loved ones. Our own complex care lead nurse works with colleagues throughout the prison to make the necessary arrangements for a dying prisoner. For instance, a prisoner may need care at night, when most are locked up, or their diet may need to be changed as their health deteriorates. The new role means that there is a single point of contact for all such issues." http://bit.ly/2m2dsIc

Updated 09.15.2019

Prison Hospice: Backgrounder

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

Photo: Lori Waselchuk. Philadelphia, PA

1. 'Organisation in collaboration sets up a project to deliver compassionate care to patients in prison settings, delivering personalised care and enabling patients to spend their last days with dignity,' *Health Service Journal*, 2019. http://bit.ly/2kRu99d

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IRELAND | *The Journal* (Dublin) – 21 September 2019 – **'The majority of Irish people believe that assisted suicide should be legalised in Ireland.'** The latest Amárach/Claire Byrne Live poll found that 55% of people think that assisted suicide should be legal in Ireland. 22% opposed the legalisation of assisted suicide, while 23% said they didn't know. Men were slightly more likely to support legalisation than women, with 58% supporting it compared to 53% of women. Young people were among the least likely to support legalisation. The poll found that 48% of 18 to 24-year-olds supported legalisation of assisted suicide, compared to 60% support among 25 to 34-year-olds and 67% among 35 to 44-year-olds. Among people aged over 55, support dropped to 49%. There was no significant difference based on social background. Those from well-off backgrounds largely backed legalisation, with support at 57%. People from lower-income backgrounds also supported changes to the law – 54% backed legalisation. http://bit.ly/2m5PkEE

Specialist Publications

Identifying patients at risk of futile resuscitation: Palliative care indicators in out-of-hospital cardiac arrest

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 17 September 2019 – Patients with indicators for palliative care (PC), such as those with advanced life-limiting conditions, are at risk of futile cardiopulmonary resuscitation (CPR) if they suffer out-of-hospital cardiac arrest (OHCA). Patients at risk of futile CPR could benefit from anticipatory care planning (ACP); however, the proportion of OHCA patients with indicators for PC is unknown. This study quantifies the extent of PC indicators and risk of CPR futility in OHCA patients. Up to 30% of OHCA patients [i.e., the patient population studied] are being subjected to advanced resuscitation despite having at least three indicators for PC. More than 80% of patients with an intermediate-to-high risk of CPR futility are dying soon after conveyance to hospital, suggesting that ACP can benefit some OHCA patients. This study recommends optimising emergency treatment planning to help reduce inappropriate CPR attempts. **Abstract:** http://bit.ly/2lXi7vc

£25 million for hospices won't go far

BRITISH MEDICAL JOURNAL | Online – 18 September 2019 – Last month the prime minister pledged a one-off payment of £25 million (€28 million; $31 million) to boost hospices and palliative care services. Boris Johnson's words were warm and supportive, hinting at more money soon. But was this more than a gesture? Certainly, the pledge is there in a Number 10 press release, including some positive reaction from the health secretary and charity chief executives at Hospice UK and Thames Hospice. Within a day of Johnson's announcement, however, the chair of National Health Services (NHS) Clinical Commissioners told the *Health Service Journal* that the £25 million would come from ring-fencing existing NHS budgets, inevitably at the expense of other cash starved services.[1] Not new money after all, then. Hospice UK recently conducted a survey on the current state of the hospice sector. Some 73% of respondents had seen the funds they received from clinical commissioning groups frozen or cut, although their own costs were rising. One in three had been forced to cut services, and around half had delayed or cancelled plans to develop or expand them. For financial context, the total NHS budget was around £125 billion for 2017-2018. But Hospice UK's figures concluded that, in 2016-2017, only 33% of hospice funding in England (about £350 million) came from government, the rest coming from charity. But why are hospices still "charitable" in a country with a national health service famously free at the point of delivery and funded from general taxation? It's a historical anomaly stemming from the separate origins of the hospice movement, which surely needs to be tackled with more than token announcements of small redirections of funding. **Full text:** http://bit.ly/2lW27cS

1. 'Funding boost for hospices promised by prime minister is not new money,' *Health Service Journal*, published online 21 August 2019. **Introduction:** http://bit.ly/2mpqOyN

Noted in Media Watch 26 August 2019 (#628, p.4):

- U.K. (England) | ITV News (London) – 21 August 2019 – **'Hospices to get £25 million cash boost to secure future…'** The government has pledged £25 million to help struggling hospices and palliative care services following an ITV News and Hospice U.K. investigation into funding for end-of-life care (EoLC). 1 in 3 hospices are being forced to cut services. More than half either have, or plan to, delay or cancel the roll out future plans to provide EoLC.[1] The cost of providing EoLC has risen in the past two years, but has not been matched by increased funding from central government. 73% have seen their funding from their local Clinical Commissioning Group had been frozen or cut. http://bit.ly/30mvpkg

    1. 'U.K. hospices face funding crisis as one in three forced to cut end-of-life services,' ITV News, 7 May 2019. [Noted in 20 May 2019 issue of Media Watch (#614, p.6)] http://bit.ly/3071bSA

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

Gaps in public preparedness to be a substitute decision-maker and the acceptability of high school education on resuscitation and end-of-life care: A mixed-methods study

CMAJ OPEN | Online – 16 September 2019 – About three-quarters of survey respondents felt prepared to be a substitute decision-maker (SDM), but almost half reported never having had a meaningful conversation with their loved ones about their wishes in the event of critical illness. Lack of this crucial conversation – the key to a SDM's understanding of the loved one's wishes, values and beliefs – strongly suggests a discrepancy between actual and perceived preparedness. This gap has also been noted in previous work, where disagreements as to whether a conversation had even taken place were common. This discrepancy between actual and perceived preparedness has direct clinical implications. Physicians should take care to ensure that SDMs fully understand their role and base their understanding of the patient's wishes, values and beliefs on reasonably detailed conversations. Some respondents noted that it could be difficult to separate their own beliefs from the patient's, highlighting that physicians should inquire about the patient's wishes in such a way as to mitigate this risk. Ideally, before acute illness strikes, chronic care physicians should meet with the patient and his or her SDM to ensure the latter has a good understanding of the role of a SDM and the patient's wishes should he or she become unable to communicate. Past work has shown that, although physicians trigger discussions regarding end of life and critical care when a patient's disease becomes severe, severity does not predict readiness for a discussion. **Full text:** http://bit.ly/2lVwUqk

Extract from *CMAJ Open* article

The high school setting provides an opportunity for universal education. This is the ideal age group for education on resuscitation and end-of-life care, given that, in Canada, the law bestows the right to act as a SDM on people at the age of 16-19 years, depending on the province or territory. Indeed, several participants described their experiences as a SDM at a young age, including respondents as young as 18.

Noted in Media Watch 10 December 2018 (#593, p.6):

- *EDUCATIONHQ* | Online – 3 December 2018 – **'English, maths and death? Doctors call for death ed in schools.'** The Australian Medical Association of Queensland (AMAQ) is calling for more education around death and dying, and want the discussion to start in schools. AMAQ has proposed an addition to the Australian curriculum to help young people cope with loss and demystify the end of life (EoL). Dr Richard Kidd says it shouldn't sound as outlandish as it might. The chair of general practice says his members have seen too many tragic incidences where young people were left to contend with the consequences of a death with little in the way of preparation. **Full text:** http://bit.ly/2kQl40n

N.B. Additional articles on the topic of dying and death in the school curriculum noted in this issue of Media Watch.

What do cancer patients' relatives think about addressing cancer family history and performing genetic testing in palliative care?

EUROPEAN JOURNAL OF HUMAN GENETICS | Online – 16 September 2019 – Palliative care (PC) may be an opportunity to discuss cancer family history and familial cancer risks with patients' relatives. It may also represent the last opportunity to collect, from dying patients, clinical data and bio-specimens that will inform cancer risk assessment and prevention in their surviving relatives. Participants in this study seemed aware that cancer family history is a potential risk factor for developing the disease. They considered the PC period an inappropriate moment to discuss cancer heritability. They also did not consider PC providers as appropriate resources to consult for such matters as they are not specialized in this field. Participants welcomed DNA bio-banking and genetic testing conducted at the PC patients' request. **Abstract (w. list of references):** https://go.nature.com/2kIjAFC

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Noted in Media Watch 2 April 2018 (#557, p.14):

- *MEDICAL LAW INTERNATIONAL* | Online – 23 March 2018 – **'Communication of genetic information in the palliative care context: Ethical and legal issues.'** The question of when and how to disclose a patient's genetic information raises a host of ethical, legal and social issues, including the challenges of communicating during the end-of-life (EoL) stage and complex familial and cultural dynamics. The authors outline the legal components of these issues in three civil law jurisdictions … and provide insights from bioethics literature and normative documents on the disclosure of genetic information at the EoL. **Abstract:** http://bit.ly/2kSdRNn

Noted in Media Watch 27 November 2017 (#540, p.13):

- *JOURNAL OF COMMUNITY GENETICS* | Online – 20 November 2017 – **'Mainstreaming genetics in palliative care: Barriers and suggestions for clinical genetic services.'** Palliative healthcare professionals (PHCPs) frequently do not refer their eligible patients for genetic testing. After the death of the affected individual, clinically relevant information for family members is lost. In previous research, PHCPs stated that the end-of-life setting is not appropriate to discuss genetic issues. It is unclear if this has changed due to increasing awareness of genetics in the media and efforts to mainstream genetic testing. **Abstract:** http://bit.ly/2kFOQFb

Primary care clinicians' confidence, willingness participation and perceptions of roles in advance care planning discussions with patients: A multi-site survey

FAMILY PRACTICE | Online – 19 September 2019 – In this survey of 174 primary care physician and non-physician clinicians in Canada, there was high willingness and confidence to engage patients in advance care planning (ACP) discussions, but low current participation. The non-physician clinicians were less confident and engaged than physicians. It was highly acceptable for family physicians, and advance practice nurses to engage patients in all aspects of ACP, from initiating to finalizing plans to helping the patient communicate their plans with family members and other healthcare professionals. It was also perceived to be acceptable for nurses, social workers and home care personnel to be involved, especially for exchanging information with patients and assisting with communication of plans to family members and other healthcare professionals. **Full text:** http://bit.ly/2kn0YKS

Palliative care in liver disease: What does good look like?

FRONTLINE GASTROENTEROLOGY | Online – 10 September 2019 – The mortality rate from chronic liver disease (CLD) in the U.K. is rising rapidly, and patients with advanced disease have a symptom burden comparable to or higher than that experienced in other life-limiting illnesses. While evidence is limited, there is growing recognition care of patients with advanced disease needs to improve. Many factors limit widespread provision of good palliative care (PC) to these patients, including the unpredictable trajectory of CLD, the misconception PC and end-of-life care are synonymous, lack of confidence in prescribing and lack of time and resources. Healthcare professionals managing these patients need to develop the skills to ensure effective delivery of core PC, with referral to specialist PC services reserved for those with complex needs. Core PC is best delivered by the hepatology team in parallel with active disease management. This includes ensuring discussions about disease trajectory and advance care planning occur alongside active management of disease complications. Liver disease is strongly associated with significant social, psychological and financial hardships for patients and their carers; strategies that involve the wider multidisciplinary team at an early stage in the disease trajectory help ensure proactive management of such issues. This review summarises the evidence supporting PC for patients with advanced CLD, presents examples of current best practice and provides pragmatic suggestions for how palliative and disease-modifying care can be run in parallel, such that patients do not miss opportunities for interventions that improve their quality of life. **Abstract:** http://bit.ly/2lOLgJ2

N.B. Additional articles on PC and liver disease noted in 22 April 2019 issue of Media Watch (#611, p.9).

Differing thresholds for overriding parental refusals of life-sustaining treatment

HEC FORUM | Online – 18 September 2019 – When should doctors seek protective custody to override a parent's refusal of potentially lifesaving treatment for their child? The answer to this question seemingly has different answers for different subspecialties of pediatrics. This paper specifically looks at different thresholds for physicians overriding parental refusals of life-sustaining treatment between neonatology, cardiology, and oncology. The threshold for mandating treatment of premature babies seems to be a survival rate of 25-50%. This is not the case when the treatment in question is open heart surgery for a child with congenital heart disease. Most cardiologists would not pursue legal action when parents refuse treatment, unless the anticipated survival rate after surgery is above 90%. In pediatric oncology, there are case reports of physicians requesting and obtaining protective custody for cancer treatment when the reported mortality rates are 40-50%. Such differences might be attributed to differences in care, a reasonable prioritization of quality of life over survival, or the role uncertainty plays on prognoses, especially for the extremely young. Nonetheless, other, non-medical factors may have a significant effect on inconsistencies in care across these pediatric subspecialties and require further examinations. **Abstract (w. list of references):** http://bit.ly/2kKwSRY

Early identification of people who would benefit from a palliative approach: Moving from surprise to routine

JAMA NETWORK OPEN | Online – 13 September 2019 – There is ample evidence that palliative interventions, including palliative care (PC) consultations, advance care planning, or goals-of-care conversations, have the potential to improve care for patients who are nearing the end of life. Professional organizations in most fields of medicine recommend the integration of a palliative approach for patients with advanced or incurable illness. Despite this, studies continue to show that many patients, especially those with non-cancer illnesses, do not receive PC prior to death or receive it only in the final days or weeks of life. One of the biggest obstacles to initiating a timely palliative approach is clinicians' inability to reliably identify people who could benefit from it. Once a patient is identified as having unmet palliative needs, they can have their specific needs assessed and managed. However, clinicians cannot perform comprehensive assessments on every patient they see; they must be selective and focus their attention on those who are most at risk. Thus, there is a need for tools that help clinicians identify the patients who most need help. Ideally, these tools would be accurate, reliable, low-cost, and integrate seamlessly into the existing workflow. The study by Ouchi *et al* presents one possible tool, the so-called surprise question, worded as "Would you be surprised if your patient died in the next one month?" in the context of emergency department visits that lead to admission to the hospital.[1] **Full text:** http://bit.ly/2mgtUoz

Prolonged survival with palliative care. It is possible, but is it necessary?

JAMA ONCOLOGY | Online – 19 September 2019 – Palliative care (PC) is defined as care provided by a specially trained team of clinicians that is both patient and family centered and seeks to enhance quality of life throughout the continuum of illness. Multiple studies have reported benefits associated with integrating early PC with standard oncology care for patients with advanced cancer to address patients' symptoms, understanding of their disease, coping strategies, and medical decision-making. Consequently, guidelines recommend early integration of PC for patients with advanced cancer, concurrently with disease-directed and life-prolonging treatment. Despite the established benefits and guideline recommendations for early integration of PC in oncology, many patients do not receive PC services or receive them late in the illness trajectory, potentially due to both patient and clinician misperceptions that PC is appropriate only after a patient has discontinued life-prolonging therapies. Thus, a growing body of literature has sought to demonstrate that PC improves patient outcomes without shortening survival. **Abstract:** http://bit.ly/2m6ddfh

1. 'Association of emergency clinicians' assessment of mortality risk with actual 1-month mortality among older adults admitted to the hospital,' *JAMA Open Network*, published online 13 September 2019. [Noted in 16 September 2019 issue of Media Watch (#631, p.12)] **Full text:** http://bit.ly/2lORh8u

State legislation to prevent diversion of opioids in hospice programs: A deeper look into Ohio law

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(5):365-372. In 2014, Ohio implemented legislation requiring a hospice employee to destroy or witness disposal of all unused opioids within a patient's plan of care. Directors of Ohio-licensed hospices were surveyed to assess the percentage of programs with a written policy in place for disposal of opioids and to calculate a compliance score based on responses to survey questions assessing compliance with legislation components. Fifty-two surveys were completed (39.4%). All survey respondents reported having a written policy in place. A 95.5% average compliance score was calculated, with the largest disparity occurring with timing of opioid disposal. While Ohio Revised Code 3712.062 requires opioid disposal at the time of patient's death or when no longer needed by the patient, only 84% of respondents report disposing opioids upon discontinuation. Overall, a high compliance rate was seen among hospice programs indicating such regulation is manageable to meet. **Abstract:** http://bit.ly/2m4F4wo

A feasibility study of home-based palliative care telemedicine in rural Nova Scotia, Canada

JOURNAL OF PALLIATIVE MEDICINE | Online – 18 September 2019 – It was recently estimated that only 30% of Canadians have reliable access to palliative care (PC) services. Allocating funding to improve access to skilled PC in rural or remote settings is challenging in an era of increasing demand and competing priorities, underscoring the need for innovative PC service delivery that optimizes use of low-cost readily available technology. This study evaluated the use of the FaceTime application on an Apple iPad to improve timely access to physician consultation for home-based PC patients living in rural Nova Scotia. Results indicated that using FaceTime through cellular data networks is feasible in rural areas of Nova Scotia. All participants reported that both the audio and visual quality allowed them to communicate easily with the doctor, and no consultations were terminated due to network instability. Patients also found the FaceTime encounter highly acceptable with 86% reporting they were "satisfied" or "very satisfied"; 100% stated that their medical concerns were addressed and 100% were willing to use FaceTime again. The results add to the limited literature exploring the application of telehealth in PC and demonstrating the utility of low-cost commonly used technology to improve access to PC in underserviced areas. **Abstract:** http://bit.ly/2mjPV5L

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

- CANADA | *The Globe & Mail* – 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/2kpqzTv

  1. 'Access to Palliative Care in Canada,' Canadian Institute for Health Information, September 2018. **Download/view (scroll down to foot of page and 'Related Links') at:** http://bit.ly/2EBoNGm

N.B. Additional articles on the role of telemedicine in PC in rural and remote regions noted in 19 August 2019 issue of Media Watch (#627, p.3).

Recognizing the dying patient, when less could be more: A diagnostic framework for shared decision-making at the end of life

JOURNAL OF PATIENT EXPERIENCE | Online – 12 September 2019 – An honest and frank discussion about likely prognosis and trajectory can appropriately temper expectations and is often appreciated by patients. Early recognition of the dying patient permits earlier discussions and thus shared decision-making in accordance with what is important to patients. This has enormous potential to increase access to high-quality patient-centered care; to improve patient and family experience; and, to save on costs from

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unwanted and futile investigations and treatments. While there is huge variety in recognizing and treating dying patients and challenges thereof between specialties, themes do emerge that would stimulate earlier consideration of palliative care (PC). The authors have therefore devised this framework as an aid to identify the dying patient earlier and facilitate shared decision-making concerning PC. There is a paucity of medical education on this topic, leaving trainees at all levels unprompted and ill prepared to plan ahead for dying patients; thus, the authors believe that this framework should be incorporated into medical school and postgraduate curricula in order to prepare doctors who are capable of providing patients with quality of death as well as quality of life. **Full text:** http://bit.ly/2kUCAR3

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

- *BMJ OPEN* | Online – 25 November 2018 – **'How do palliative care doctors recognise imminently dying patients? A judgement analysis.'** The National Institute for Health & Care Excellence guideline on end-of-life care describes the recognition of imminent death as an essential first step towards improving care for dying patients.[1] However, the guideline does not clearly explain how doctors are expected to identify such patients, nor how novice doctors can be expected to learn or improve this clinical skill. **Full text:** http://bit.ly/2RR5XmC

    1. 'Care of dying adults in the last days of life,' National Institute for Health & Care Excellence, December 2015. [Noted in 21 December 2015 issue of Media Watch (#441, p.7)] **Download/view at:** http://bit.ly/2Tj0xxD

N.B. Additional articles on awareness of imminent or impending death noted in 25 June 2018 issue of Media Watch, #569, p.10.

Impact of the Liverpool Care Pathway on quality end-of-care in residential care homes and home care: Nurses' perceptions

NURSING OPEN | Online – 9 September 2019 – In spite of a solid evidence base for effective interventions to meet the needs of the dying person and their family, implementation of best practice is still a challenge. One suggested way to promote high-quality end-of-life care (EoLC) is to use integrated care pathways, that is structured assessments and evaluations of a patient's symptoms and needs, together with a description of process and clear goals for the patient's care. The Liverpool Care Pathway (LCP) for dying patients is one such tool used bedside to promote optimal care of the dying in the last days and hours of life, aiming to transfer best practice from hospice settings to other care setting. The LCP includes decision-making support to identify imminent death, pharmacological and non-pharmacological strategies for symptom management and communication with the dying person and their family. The LCP was initially developed to ensure high-quality EoLC for patients with cancer but has also been shown to be appropriate irrespective of diagnosis and is now used also in other care settings including residential care homes and home care. However, since the Neuberger report from the U.K. Department of Health, the LCP has been criticized and its benefits questioned.[1] Although the report acknowledged positive effects of the LCP when used as intended, the authors highlighted the risk of poor care related to inappropriate implementation and lack of competence in EoLC. Not least, malpractice was evident in older, non-cancer patients. The need for scientific evidence for the use of integrated care pathways, including the LCP, in EoLC is evident as is the need for studies focusing quality care in a comprehensive way. This is especially true for the care of the dying in community care settings. **Full text:** http://bit.ly/2mkR65f

1. 'Review of Liverpool Care Pathway for Dying Patients,' Department of Health, July 2013. [Noted in 22 July 2013 issue of Media Watch (#315, p.6)] **Download/review at:** http://bit.ly/2khETNO

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Noted in Media Watch 12 August 2019 (#626, p.6):

- *BRITISH JOURNAL OF NURSING*, 2019;28(15):1001-1007. **'Palliative care after the Liverpool Care Pathway: A study of staff experiences.'** This study explores nurses' perceptions of end-of-life care following the withdrawal of the Liverpool Care Pathway (LCP). Thirteen semi-structured interviews were conducted with nurses working in palliative care (PC). Three themes emerged: 1) Perceptions of the LCP; 2) Prevailing issues; and, 3) Patients' and families' experiences. The removal of the pathway has not remedied the issues attributed to it. Further, the way in which the LCP was removed indicates that the non-expert media can play a negative role in how PC is perceived, which inhibits the care process. In this respect it is important that "insider" voices are also heard, in order to educate and also redress disinformation. **Abstract:** http://bit.ly/2M9ivm5

Noted in Media Watch 5 March 2018 (#553, p.13):

- *WELLCOME OPEN RESEARCH* | Online – Accessed 27 February 2018 – **'The Liverpool Care Pathway for the Dying Patient: A critical analysis of its rise, demise and legacy in England.'** The Liverpool Care Pathway for the Dying Patient ("the LCP") was an integrated care pathway recommended by successive governments in England & Wales to improve end-of-life care (EoLC), using insights from hospice and palliative care. It was discontinued in 2014 following mounting criticism and a national review. The ensuing debate among clinicians polarised between "blaming" of the LCP and regret at its removal. The authors aimed to address three questions: 1) Why and how did the LCP come to prominence as a vehicle of policy and practice; 2) What factors contributed to its demise; and, 3) What immediate implications and lessons resulted from its withdrawal? **Full text:** http://bit.ly/2ZIiYyY

Palliative care in primary care: European Forum for Primary Care position paper

PRIMARY HEALTH CARE RESEARCH & DEVELOPMENT | Online – 18 September 2019 – The aim of this position paper is to assist primary healthcare (PHC) providers, policymakers, and researchers by discussing the current context in which palliative healthcare functions within PHC in Europe. The position paper gives examples for improvements to palliative care (PC) models from studies and international discussions at European Forum for Primary Care (EFPC) workshops and conferences. There is great diversity in the extent and type of PC provided in primary care by European countries. Primary care teams (PCTs) are well placed to encourage timely PC. The authors collected examples from different countries. They found numerous barriers influencing PCTs in preparing care plans with patients. The authors identified many facilitators to improve the organization of PC. **Abstract (w. list of references):** http://bit.ly/2ku8CDs

Future-proofing the palliative care workforce: Why wait for the future?

PROGRESS IN PALLIATIVE CARE | Online – 16 September 2019 – 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. More recently, 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] Future workforce challenges for PC are thus foreseeable not only from increased demand associated with population growth and ageing, but also a decrease in supply as a significant proportion of the PC workforce retire or otherwise leave this speciality area of practice, with insufficient numbers being trained to cover the shortfall. This is reflected in a projected ratio of one PC physician per 26,000 American patients eligible for PC in 2030, if significant action is not taken soon. **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

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Noted in Media Watch 19 February 2018 (#551, p.6):

- *AMERICAN JOURNAL OF MEDICAL QUALITY* | Online – 7 February 2018 – **'Hospice care needs study.'** Medical schools have attempted to integrate hospice and palliative medicine (HPM) curricula for more than 20 years. Despite these initiatives, gaps in both education and numbers of qualified providers still exit, and hospice remains largely misunderstood by patients and medical professionals alike. A task force convened by the American Academy of Hospice & Palliative Medicine found an acute shortage of HPM physicians and reported that current fellowship programs are insufficient to fill the shortage.[1] **First page view:** http://bit.ly/2Wn6qPO

    1. 'Estimate of current hospice and palliative medicine physician workforce shortage,' *Journal of Pain & Symptom Management*, 2012;40(6):899-911. [Noted in 13 December 2010 issue of Media Watch (#179, p.9)] **Full text:** http://bit.ly/2QNii7Q

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. This ratio varies greatly across the country. Using alternate assumptions for future supply and demand, the authors project need in 2040 will range from 10,640 to almost 24,000 HPM specialist physicians. Supply will range from 8,100 to 19,000. Current training capacity is insufficient to keep up with population growth and demand for services. **Full text:** http://bit.ly/2CRjxwO

Family caregivers' anticipatory grief: A conceptual framework for understanding its multiple challenges

QUALITATIVE HEALTH RESEARCH | Online – 16 September 2019 – The end-of-life (EoL) trajectory of cancer patients in palliative care (PC) elicits an anticipatory grief (AG) process in family caregivers (FCGs). Although widely recognized, AG lacks conceptual clarification. This study aims to qualitatively explore the experience of FCGs of patients with terminal cancer to identify the core characteristics and the specific adaptive challenges related to AG in the context of EoL caregiving. Findings from this study suggest that the AG experience is characterized by traumatic distress from being exposed to life-threatening conditions and the separation distress induced by loss anticipation and current relational losses, challenging the FCGs to long-term emotional regulation effort demands. These results contribute to the conceptualization of AG and may inform intervention programs for the main challenges the FCGs face when adjusting to loss during EoL caregiving. **Abstract:** http://bit.ly/2kuaLPw

Psychosocial care provision for terminally ill clients in rural Australian communities: The role of social work

RURAL & REMOTE HEALTH | Online – 19 September 2019 – This study explored questions relating to the nature of psychosocial care provision in rural and remote Queensland. It also identified enablers and barriers to social work referrals for psychosocial care in the rural context. Social workers have psychosocial expertise, yet there is very little literature regarding their involvement with terminally ill clients. This study is one of the first to highlight the generalist social work role with palliative clients in rural regions and the substantial challenges social workers encounter when working across a geographically vast landscape. The study incorporated the perspectives of palliative care clients to explore their perspectives about how psychosocial needs were met. Implications and recommendations for education and training for health practitioners and the social work profession highlight the need to address skills and competencies in psychosocial care for terminally ill clients. The aim is for future social workers to feel more confident in their capabilities to address psychological, emotional, social, spiritual and cultural issues as they arise. However, support is required from a university curriculum level as well as an endorsed national standards and competencies document to serve as fundamental foundations. Despite this study being undertaken in one Australian state, the findings are consistent with those experienced in countries such

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as Canada and the U.S. where geographical distances created barriers to timely interventions that influenced the effectiveness of the provision of psychosocial care in many rural communities. While death is an inevitable outcome for us all, measures need to be undertaken to ensure good psychosocial care is also an outcome, before and after the event. Advocating for those who are vulnerable is a must for health professionals. A lone voice is not enough. **Full text:** http://bit.ly/2kKi7P6

> **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 16 September 2019 issue of Media Watch (#631, p.5).

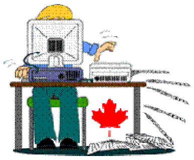
Assisted (or facilitated) death

Representative sample of recent journal articles:

- *HAWAII JOURNAL OF HEALTH & SOCIAL WELFARE*, 2019;78(7):236-239. **'Education and end-of-life options: Hawaii's 'Our Care, Our Choice Act.'** Several grey areas regarding medical aid in dying (MAiD) must be discussed and explored. This includes institutional workplace policies, which are likely to impact the ability to allow MAiD at inpatient facilities. Financial issues may also be a concern, as the significant cost of MAiD medications is not covered by federal dollars funded via Medicare, Medicaid, or the Veterans Administration. Additionally, understanding the motivations and desires at the end of life (EoL), such as caregiver support, or patients' desire to not want to be a burden on loved ones, may lead to hasty decisions in requesting MAiD. Terminally ill patients also need to understand the need for a strong caregiver support to help facilitate the process of MAiD since the process is fundamentally patient-led and occurs outside of a healthcare setting. Training in geriatric medicine, hospice services, and palliative care (PC) will lead to a better understanding of EoL care, and hence better care for patients. This includes a thorough understanding of EoL options, which may include MAiD if requested, as well as, understanding the availability of skilled hospice services and PC that are covered by insurance. For many people, hospice services will replace the fear or motivation that leads to a request for MAiD. **Full text:** http://bit.ly/2lRqBnw

- *NEUROLOGY* | Online – 17 September 2019 – **'End of life: Expert care and support, not physician-hastened death.'** In legal physician-hastened death, a physician prescribes medication with the primary intent of causing the death of a willing terminally ill patient. This practice differs radically from palliative sedation, intended to relieve a patient's suffering rather than cause a patient's death. In this position paper, the authors argue that the practice of physician-hastened death is contrary to the interests of patients, their families, and the sound ethical practice of medicine. Therefore, the American Academy of Neurology should advise its members against this practice, as it had done until 2018. **Abstract:** http://bit.ly/2lWQTF6

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 17 September 2019 – **'Barriers to access: A feminist analysis of medically-assisted dying and the experience of marginalized groups.'** In this article, the author argues that a holistic strategy is needed to ascertain how implicit bias, on the part of healthcare providers, and structural impediments work together to produce significant barriers to access to medical assistance in dying for marginalized groups – particularly those experiencing intersecting or interlocking forms of identity-based oppressions. In doing so, she also make the case that this kind of primary, patient-centered, and institutional research could benefit from the insights of critical feminism and materialist feminist theory by highlighting and challenging inequalities, opening up debate, and exploring new forms of knowledge production. **Abstract:** http://bit.ly/2msW67X



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

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