

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

Only when we are able to accurately identify where people want to spend their last days, can we begin to meet the needs of patients as they approach the final stage of their lives.

*'Preferences for place of care and place of death: What, how, when and who to ask?' (p.15), in *Progress in Palliative Care*.*

Canada

Health Canada drafts policies for special access to medicines program

REGULATORY FOCUS | Online – 13 May 2019 – Similar to the U.S. Food & Drug Administration's expanded access program, which allows for those with serious or life-threatening conditions to gain access to experimental medicines, Health Canada opened a draft guidance consultation on changes to its Special Access Program (SAP) for drugs. The 29-page draft guidance builds on previous guidance adopted in 2014 and explains how Canadian health care practitioners can obtain access to an unauthorized drug for emergency treatment of a serious or life-threatening condition if conventional therapies have failed, are unsuitable or are unavailable either on the market or via clinical trial enrollment. New to the scope of the SAP guidance is draft information on the process to request a reconsideration review prior to the issuance of a request denial and a personalized service for urgent life-threatening or end-of-life situations." <http://bit.ly/2E3u9JJ>

Personalized service for urgent life-threatening or end-of-life situations

A personalized service is available to physicians treating patients in urgent situations due to a critical or terminal illness. A 24-hour direct service line will continue to be available to physicians on a triage-based approach (i.e., severity of condition and immediate need of treatment). This service provides physicians with the option to access a Health Canada healthcare professional and will allow direct communication between Health Canada and physicians. It is important to note that manufacturers still have the final decision on whether the drug will be supplied to the physician and whether any restrictions or conditions will be imposed on the release of the drug.

N.B. Download/view 'Draft guidance document for industry and practitioners on the Special Access Program (SAP) for drugs' at: <http://bit.ly/2W70mtE>



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Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ONTARIO | CBC News (Toronto) – 15 May 2019 – **‘Ontario’s highest court rules doctors must give referrals for services they oppose.’** Doctors in Ontario are obligated to give referrals for medical services that clash with their moral or religious beliefs, the province’s highest court has ruled. In a 74-page ruling ... a three-judge panel of the Court of Appeal for Ontario sided with an earlier divisional court decision that upheld the referral requirement. The requirement is part of a policy issued by the College of Physicians & Surgeons of Ontario to address issues surrounding, among other things, assisted dying and abortion and other services to which a physician may object to “on the basis of religion or conscience.” Last year, the divisional court found that while the policy does infringe on doctors’ religious freedom, the benefits to the public outweigh the cost to physicians. <http://bit.ly/2Q4LSFj>

Specialist Publications

‘Voluntary euthanasia, assisted suicide and law reform: A sketch of the Canadian experience’ (p.17), in *BioLaw Journal*.

‘Suicide vs. medical assistance in dying (MAiD): A secondary qualitative analysis’ (p.17), in *Death Studies*.

‘Medical assistance in dying: A review of Canadian nursing regulatory documents’ (p.17), in *Policy, Politics & Nursing Practice*.

U.S.A.

Hospices look to millennials to fill staff shortages

HOSPICE NEWS | Online – 17 May 2019 – As hospices stare down widespread staff shortages across all disciplines, many are looking to the millennial generation to fill those gaps, adapting recruitment and retention strategies to potential employees who came of age in a very different cultural environment than their baby boomer or Generation X colleagues. Hospices are already struggling to fill their ranks. The U.S. has 13.35 hospice and palliative care (PC) specialists for every 100,000 adults 65 and older, according to an April 2018 study.¹ The research estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000. Hospice and PC providers also experience shortages in non-physician disciplines, including chaplains, nurses, and social workers. As far back as 2008, the U.S. Centers for Medicare & Medicaid Service began allowing hospice providers to use contracted nursing staff because not enough nurses were available to fill permanent positions. <http://bit.ly/2Holfas>

1. ‘The growing demand for hospice and palliative medicine physicians: Will the supply keep up?’ *Journal of Pain & Symptom Management*, published online 2 February 2018, noted in 5 February 2018 issue of *Media Watch*, #549, p.12. **Full text:** <http://bit.ly/2CRjxwO>

Where should a child die? Hospice homes help families with the unimaginable

THE NEW YORK TIMES | Online – 15 May 2019 – A children’s hospice home like Crescent Cove is not an option for most of the roughly 43,000 children who die every year in the U.S. There are many such facilities that care for terminally ill adults; there are several, at least, in every state. But while some of them may take in pediatric patients, there are only three houses in the country that have been specifically designed for children. Crescent Cove, which began accepting patients last May, is the latest to open; the other two are in San Leandro, in Northern California, and Phoenix. By some estimates, around half a mil-

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lion children have serious medical conditions that are expected to shorten their lives. For too many of them, death will most likely happen amid the fluorescence and thrumming machinery of an intensive-care unit. Hospice care in the U.S., envisioned and developed to meet the needs of dying adults, was first conceived as in-home services. Such support is not always available for children, and when it is, it is often inadequate. The federal government has been paying for and regulating end-of-life care for adults since the passage of the Medicare Hospice Benefit Act in 1986. Hospice organizations, thriving on Medicare's payments, have proliferated to number more than 4,500, but only something like 10% of them will care for children. <https://nyti.ms/30nsNCV>

Senate seeks to extend time in end-of-life hospital disputes

TEXAS | *Austin American-Statesman* – 14 May 2019 – After a 12-year legislative fight over end-of-life disputes, the Texas Senate passed a bill that would extend the waiting period for doctors to withdraw life support from a patient whose family wants to keep the person alive. Senate Bill 2089 would extend the current 10-day period to a “mid-range” 45 days, a move ... [that] ... would address the time concerns of families whose loved ones were removed from life support. But opponents of the bill say current practice, which was considered a breakthrough when signed by then-Governor George Bush in 1999, is sufficient to balancing a doctor's Hippocratic oath with a patient's and family's wishes. In Texas, if doctors believe continued treatment would inhumanely extend a patient's suffering in a way that violates the doctor's oath to do no harm, they can overrule family wishes by asking the hospital's ethics committee for approval to halt life-sustaining care – which can include withholding dialysis and ventilators – after the 10-day period. Patients and their families have this time to find a doctor or hospital that agrees to keep the patient alive. <https://atxne.ws/2WJNBCr>

Base hospice on patient needs, not six-months prognosis

HOSPICE NEWS | Online – 10 May 2019 – The person-centered, interdisciplinary care model applied by hospice providers should not remain cocooned within the six-month Medicare benefit. This according to Edo Banach, who in 2017 after years of legal practice and government posts with the City of New York and the U.S. Centers for Medicare & Medicaid Services took the helm as president of the National Hospice & Palliative Care Organization, the largest non-profit membership organization for hospice and palliative care providers and professionals. The question of whether someone is eligible for hospice should be linked to their medical and non-medical needs, and “needs” does not mean six months. A person with dementia, for example, may have the need for interdisciplinary person-centered care for a really long time. But when you focus on the six-month prognosis, the hospice is under tremendous pressure to discharge that patient alive. Then that person either returns to hospice or decompensates, goes into a hospital, then goes into a nursing home, and then comes back to hospice. And by then we have spent a million dollars for no good reason. <http://bit.ly/2HekiCU>

What if the homeless had a place to die with dignity?

UTAH | *Washington Examiner* (Washington DC) – 10 May 2019 – Most of us have wondered what it would be like to live on the streets. But I'd imagine few of us have ever considered what it would be like to die there. Thousands of homeless people perish under bridges and in alleyways every year. In Salt Lake City last year, about 50 people breathed their last breath without even the modest comfort of a safe home, a warm room, or a dry bed. That number would have been even higher if not for the existence ... of one of the nation's only hospice facilities for homeless people. <https://washex.am/2VhvWYy>

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



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

International

Brief manual health indicators monitoring global palliative care development

SPAIN | Instituto Cultura y Sociedad Universidad de Navarra – Accessed 17 May 2019 – The objective of this initiative is to present a set of national-level indicators to assess the development of palliative care (PC) in different countries and regions. The resulting indicators from a consensus process with an international panel comprised of professionals in PC with extensive experience in cross-national assessment of PC development, research and advocacy. Global and international PC associations have endorsed the indicators presented in this manual. Since indicators should be adjusted to the national and regional contexts, their implementation in such studies should be preceded by discussion on the feasibility of each indicator in their specific contexts. **Download/view at:** <http://bit.ly/2Vsgt0l>

Is it time we change the way we remember the dead?

U.K. | *National Geographic* – 17 May 2019 – Roughly 600,000 people will die in the U.K. in 2019. Modern lives are busy, so what happens on when that life ends from a collective, cultural point of view probably isn't on most people's minds. You'll have a funeral. It'll be dealt with. Somehow, somewhere. Right? Yet, for a subject so marginalised amongst the living, the memorialising and memory of the dead is an intrinsic part of cultures across the world – and a part that requires the upmost sensitivity both to talk about, let alone to change. But how will the living be remembered in the future, when we live in a present that's seeing overflowing cemeteries, dwindling land resources, rising funeral costs and changing attitudes? And who will conserve the memory of those of previous generations – whose crumbling legacy lies in churchyards and cemeteries across the country – that forms such a critical part of our national heritage and aesthetic? <http://bit.ly/2HDaHVg>

Adopt new policy standards for terminally ill patients with substance use problems, says report

U.K. (England) | *About Manchester* – 16 May 2019 – Researchers ... have outlined six policy standards urging policy-makers, National Health Service (NHS) commissioners and service providers to introduce measures that would improve provision and tackle stigma towards terminally ill patients who are, or have been, problematic users of alcohol or other drugs.¹ The recommendations – the first of their kind in the U.K. – are based on consultation with professionals in leadership and policy roles across health and social care services in Liverpool, particularly specialist palliative, end-of-life and substance use services. The report's authors call on national and local strategic health bodies to begin work jointly with NHS trusts, local authorities and third-sector organisations to develop policy standards that will support service delivery and reduce health inequalities for this vulnerable group of people. <http://bit.ly/2W65Hle>

1. 'Policy Standards: A Working Document. Palliative and End of Life Care for People with Alcohol and Drug Problems,' (1st edition), Manchester Metropolitan University, May 2019. **Download/view at:** <http://bit.ly/2w0StY3>

N.B. Additional articles on terminal ill patients with drug and alcohol addictions noted in 19 November 2018 issue of *Media Watch*, #590, pp.13-14.

Specialist Publications

'Waiting for a miracle or best medical practice? End-of-life medical ethical dilemmas in Bahrain' (p.7), in *BMJ Journal of Medical Ethics*.

'Most GPs [in the U.K.] have too little time to discuss end-of-life care' (p.10), in *GP*.

'Urban and rural differences in geographical accessibility to inpatient palliative and end-of-life care facilities and place of death: A national population-based study in England, U.K.' (p.15), in *International Journal of Health Geographics*.

'A qualitative study on existential suffering and assisted suicide in Switzerland' (p.17), in *BMC Medical Ethics*.

£250,000 cut to Telford hospice's grant was "necessary," says health boss

U.K. (England) | *The Shropshire Star* (Telford) – 14 May 2019 – The decision to cut funding to Severn Hospice by nearly a quarter was necessary in a "particularly challenging financial year," a local National Health Service chief has said. Telford & Wrekin Clinical Commissioning Group's annual grant to Severn Hospice stood at £1.1 million for three years, but goes down to £850,000 from 2019-2020. In response, the charity is to close two beds at its Telford in-patient centre at Apley Castle <http://bit.ly/30fywLf>

Online plan to let dying people share their wishes backed by Health Secretary

U.K. (England) | BT News (London) – 13 May 2019 – The Health Secretary is backing a new online National Health Service scheme where people who are dying can share their wishes around treatment and care. Matt Hancock welcomed the move towards giving chronically ill patients and those nearing death more control of what happens in an emergency, such as whether they would want to be resuscitated or if they wish to die at home. The online plan, myCMC (my Co-ordinate My Care), enables details to be shared between care providers such as 111 [a medical helpline], out-of-hours GPs, and the ambulance service. Other details can include emergency contacts, a patient's cultural or spiritual beliefs, whether they wish to donate their organs and whether they have a pet that needs to be cared for in an emergency. <http://bit.ly/2E6Q3vL>

N.B. Co-ordinate My Care website: <http://bit.ly/2HiwQJw>

Cash-strapped hospice launches new appeal to help care for babies

U.K. (England) | *The Northern Echo* (Darlington, County Durham) – 9 May 2019 – Zoe's Place in Middlesbrough has launched a new campaign urging everyone in the region to raise £29 each to fund one hour of vital care for a baby and family in need. The new appeal comes after the hospice warned they were in the "most challenging times" they'd ever faced and could be forced to close for two nights a week due to financial hardship, meaning they would be unable to offer emergency respite for families. The hospice, which needs £1.5 million a year to keep its doors open, has cared for more than 350 children across the North-East since opening in 2004, and at the moment has more than 30 babies and young children receiving regular nursing care. <http://bit.ly/2JyWawb>

For many, "death is a gentle, peaceful and pain-free event"

U.K. | *Newsweek* – 8 May 2019 – An expert has stressed that death is a "gentle, peaceful and pain-free event" for many people, after a survey revealed six in ten people feel they know little or nothing about what happens in our final moments. The poll of 966 adults in the U.K. ... also revealed one in two people have been beside someone as they died. When their fears about accompanying a person as they died were probed, 62% said they were worried loved ones would be in pain, while 52% were concerned it might be frightening for the person, and 40% said they worried the person passing away might panic. Asked how they learn about the process of dying, 33% of participants who took part in the face-to-face poll conducted by Ipsos MORI for the Academy of Medical Sciences said they take information from personal experience, and a further 42 said they learned from family and friends. Of those who said they knew a little about dying, a fifth said they were informed by documentaries, 22% by medical professionals, and a further 16% by films, dramas, and soap operas. <http://bit.ly/2vQ2h7m>

Related

- U.K. (England) | *The Guardian* (London) – 5 May 2019 – **'Welcome to the Departure Lounge. Destination: death.'** Death is one of the most under-researched areas in healthcare, accounting for less than half of 1% of money spent. The idea of the Departure Lounge is to enable visitors to ask any questions they might have about the dying process, and also to collect ideas and experiences that could inform future research. The best time to have conversations about death probably isn't when you're confronting it, but well before... the hope is that the Departure Lounge will attract people who might not be regular visitors to science museums. <http://bit.ly/2Y6TObR>

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Noted in Media Watch 25 May 2015 (#411, p.7):

- U.K. | *The Guardian* (London) – 18 May 2015 – **‘Few Britons discuss dying or make plans in event of their death, finds survey.’** Few Britons have discussed their death. While more than 30% of people think about their death at least once a week, nearly three-quarters believe fellow Britons are uncomfortable discussing dying and bereavement, according to a poll by the Dying Matters Coalition.¹ A mere 7% had discussed what sort of care they might want if they are unable to make their own decisions, while only 18% said they had spoken to a family member about the way they might want to end their life. <http://bit.ly/2Lo9rKH>

1. ‘Public Opinion on Death and Dying,’ National Council for Palliative Care, May 2015. **Download/view at:** <http://bit.ly/2WnKGPG>

Why palliative care is not getting the attention it deserves in Hyderabad

INDIA (Karnataka) | *The News Minute* (Bangalore) – 7 May 2019 – Although there has been some progress in the last five years, Hyderabad and India, in general, are poorly equipped to provide palliative care (PC). It is estimated that less than 3% of patients in India have access to adequate PC. India ranks last in the list of 40 countries when it comes to the availability of painkillers for end-of-life care. Awareness of PC is essential for patients with terminal or life-threatening illnesses so that they can forgo a lot of the pain associated with their treatment. This cause has been widely acknowledged by several other countries and even the World Health Organisation ... urging countries to invest in primary healthcare, which includes PC, as the first step to universal healthcare. The National Programme for Palliative Care (NPPC) was formed in 2012 with a goal to improve availability and accessibility of rational, quality pain relief and PC to the needy, as an integral part of healthcare at all levels. This programme has a huge scope to integrate PC into the public health system and remains under-utilised. Only in October 2017 did the Telangana government finally tap into the available funding provided by the NPPC when they built a five-bed PC centre in the Area Hospital in Chevella and built seven more such centres in each district in Telangana. While it is laudable that Telangana is better equipped for PC than a majority of other states, it is pertinent to note that Hyderabad has only one government hospital that offers PC treatment. <http://bit.ly/2DXbfnT>

U.K. hospices face funding crisis as one in three forced to cut end-of-life services

U.K. | *ITV News* (London) – 7 May 2019 – An *ITV News* investigation has found hospices in the U.K. are facing a funding crisis, with increasing demand and rising cost of end-of-life care (EoLC) not being matched by government funding. An exclusive survey with Hospice UK found 1 in 3 hospices are being forced to cut services, while more than half (55%) either have, or plan to, delay or cancel the roll out future plans to provide EoLC – 90% of hospices who responded said they did not believe they have the resources to meet the rising demand. For 89% of hospices who responded, the cost of providing EoLC had 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. The average adults hospice in the U.K. receives 30% of its funding from government health budgets, for children’s hospices it is 22%. In Wales and Scotland health spending is devolved – the rest must be raised through fundraising. <http://bit.ly/3071bSA>

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>



Specialist Publications

Well-being at the end of life

ANNUAL REVIEW OF SOCIOLOGY | Online – 13 May 2019 – This review proposes that the end of life (EoL) is a uniquely contemporary life course stage. Epidemiologic, technological, and cultural shifts over the past two centuries have created a context in which dying has shifted from a sudden and unexpected event to a protracted, anticipated transition following an incurable chronic illness. The emergence of an EoL stage lasting for months or even years has heightened public interest in enhancing patient well-being, autonomy, and the receipt of medical care that accords with patient and family members' wishes. The authors describe key components of EoL well-being and highlight socioeconomic and race disparities therein, drawing on fundamental

cause theory. They describe two practices that are critical to EoL well-being (advance care planning and hospice) and identify limitations that may undermine their effectiveness. The authors conclude with recommendations for future sociological research that could inform practices to enhance patient and family well-being at the EoL. **Abstract:** <http://bit.ly/2LHcnIN>

Publishing Matters

'Academics raise concerns about predatory journals on PubMed' (p.18), in *The Scientist*.

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 14 May 2019 – '**The impact of advance care planning on end-of-life care: Do the type and timing make a difference for patients with advanced cancer referred to hospice?**' A verified do-not-resuscitate (DNR) order prior to the last 30 days of life was associated with reduced odds of admission to hospice compared to those without a DNR order. An advance care planning (ACP) note in the problem list prior to the last 30 days of life was associated with reduced odds of admission compared to those without an ACP note, and further reduced odds if done 6 months prior to death. Improving ACP processes prior to hospice referral holds promise for reducing end-of-life admissions. **Abstract:** <http://bit.ly/2JHdhw4>

Doctors' perceptions of how resource limitations relate to futility in end-of-life decision making: A qualitative analysis

BMJ JOURNAL OF MEDICAL ETHICS | Online – 15 May 2019 – Ninety-six doctors were interviewed in 11 medical specialties [at three tertiary hospitals in metropolitan Brisbane, Australia]. Doctors' perceptions of whether resource limitations were relevant to their practice varied, and doctors were more comfortable with explicit rather than implicit rationing. Several doctors incorporated resource limitations into their definition of futility. For some, availability of resources was one factor of many in assessing futility, secondary to patient considerations, but a few doctors indicated that the concept of futility concealed rationing. Doctors experienced moral distress due to the resource implications of providing futile treatment and the lack of administrative supports for bedside rationing. Doctors' ability to distinguish between futility and rationing would be enhanced through regulatory support for explicit rationing and strategies to support doctors' role in rationing at the bedside. Medical policies should address the distinction between resource limitations and futility to promote legitimacy in end-of-life decision making. **Abstract:** <http://bit.ly/2Q7b3XY>

Waiting for a miracle or best medical practice? End-of-life medical ethical dilemmas in Bahrain

BMJ JOURNAL OF MEDICAL ETHICS | Online – 15 May 2019 – In Bahrain, maintaining life support at all costs is a cultural value considered to be embedded in the Islamic religion. The authors explore end-of-life (EoL) decision making for brain dead patients in an Arab country where medical cultures are dominated by Western ideas and the lay culture is Eastern. Participants in this study considered it difficult to engage non-medical people in EoL decisions because of people's reluctance to talk about death and no le-

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gal clarity about medical responsibilities. There was disagreement about doctors' roles with some saying that EoL decisions were purely medical or purely religious but most maintaining that such decisions need to be collectively owned by medicine, patients, families, religious advisors and society. Participants practised in a legal vacuum that made their ethics interpretations and clinical decision making idiosyncratic regarding EoL care for brain dead patients. Participants referred to contrasts between their current practice and previous work in other countries, recognising the influences of religious and cultural dimensions on their practice in Bahrain. **Abstract:** <http://bit.ly/2HnnDPY>

N.B. Additional articles on the Islamic perspective on EoL and EoL care noted in 4 March 2019 issue of Media Watch, #604, pp.5-6.

Imminent death: Clinician certainty and accuracy of prognostic predictions

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 10 May 2019 – The results of this study show that even when patients are very confident that a patient will die within the next 72 hours, these estimates are only correct on 75% of occasions (and at the expense of a high number of indeterminate cases). It is therefore important for clinicians to convey this level of uncertainty in their communications with patients and relatives and not to forget that even their most confident predictions are inaccurate 25% of the time. This suggests that while clinical predictions will continue to have a role for routine prognostication, other approaches (such as the use of prognostic scores) may be required for those cases where doctors' estimates are indeterminate. **Full text:** <http://bit.ly/2Hevs9p>

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.

Electronic palliative care coordination systems (EPaCCS): A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 8 May 2019 – While innovation to improve the quality of care received by patients is highly desirable, widely promoting interventions in the absence of strong supporting evidence can be dangerous. Logical and well-intentioned policy recommendations can do more harm than good. The studies described in this systematic review highlight the important potential benefits of EPaCCS for improving the end-of-life care. However, observational studies can overestimate the effect of interventions, and the lack of strong evidence is of concern. All interventions may have benefits and harms, some of which are more predictable than others. **Full text:** <http://bit.ly/2Jvp5kQ>

Noted in Media Watch 19 September 2016 (#480, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 13 September 2016 – '**Crash course in Electronic Palliative Care Coordination Systems: 8 years of successes and failures in patient data sharing to learn from.**' EPaCCS are England's pre-eminent initiative in enabling advance care planning and improved communication and coordination at the end of life. EPaCCS are electronic registers or tools and processes for sharing data which aim to enable access to information about dying patients. Striking outcomes have been reported around EPaCCS, such as 77.8% of 'Coordinate My Care' patients dying in their preferred place. EPaCCS have, however, been extremely challenging to develop and implement, with many projects remaining continuously "under development" or folding. **Full text:** <http://bit.ly/2VmEMgE>

End-of-career practice patterns of primary care physicians in Ontario, Canada

CANADIAN FAMILY PHYSICIAN, 2019;65(5):e221-e230. This study documented the end-of-career practice patterns of Ontario primary care physicians between 1992 and 2013 and revealed that retirement is a gradual process that unfolds differently for different physicians. For more accurate prediction of physician retirement trends and effective work force planning, the study highlights the importance of considering physician workload, scope of practice, and demographic characteristics. It also sets the stage for further research: multivariate modeling is needed to quantify the effect of various factors on workload and scope of practice. Research using qualitative methods to clarify underlying reasons for the patterns observed, and to explore the broader context in which retirement decisions are made, will enrich understanding of end-of-career issues among physicians. Finally, because the issues the authors explored are equally relevant to the specialty physician work force, a similar study of medical and surgical specialists is necessary. **Full text:** <http://bit.ly/2WVNaoZ>

Pediatric palliative care in the medical neighborhood for children with medical complexity

FAMILIES, SYSTEMS & HEALTH | Online – 2 May 2019 – Children with medical complexity (CMC) are a medically fragile pediatric population that experience severe chronic illnesses resulting in significant healthcare needs, functional limitations, and healthcare utilization, and are at the highest risk for morbidity and mortality among all children. Furthermore, families and parents of CMC experience significant caregiver hardships and diminished quality of life. The field of pediatric palliative care (PC) has grown in recent years, in part to address the physical and psychosocial issues inherent to the care of these chronically ill children. However, as the prevalence and long-term survival of CMC increases with medical advancements, the demand for pediatric PC will likely exceed the capacity of current and future pediatric PC specialists. Therefore, alternative strategies to ensure access to essential aspects of PC must be considered. The authors discuss how PC principles naturally align with and complement the goals of the CMC medical home. They detail what actions pediatric PC specialists can take to best support the CMC medical home as “medical neighbors.” Lastly, the authors describe the fun-

damental aspects of pediatric PC that all clinicians caring for CMC should be able to provide, referred to as “primary pediatric palliative care.”

Abstract: <http://bit.ly/2PU37sO>

Bereavement counselling for healthcare workers in the aftermath of child death

IRISH MEDICAL JOURNAL, 2019;112(5). This study highlights the need to improve staff awareness of the counselling services that are available and the need to proactively approach staff to offer these supports after paediatric patient deaths and other serious adverse events. Ideally the scope of bereavement counselling could be extended to allowing time for self-healing activities for individuals while at work. The literature shows that meditation, journaling, prayer, and quiet time may be therapeutic for healthcare workers. Other methods to encourage self-healing that could be used include yoga, tai chi, relaxation exercises, and music. The Health Service Executive (HSE) undertook a review of methodologies which can assist in the provision of a “graduated and proportionate response” to the review of incidents as identified in the HSE’s Incident Management Framework (2018). **Full text:** <http://bit.ly/2JfXk07>

Related

- *BMJ OPEN* | Online – 9 May 2019 – ‘**Parental experiences of end-of-life care decision-making for children with life-limiting conditions in the paediatric intensive care unit: A qualitative interview study.**’ This study adds to the limited evidence base related to parental experiences of end-of-life care (EoLC) decision-making and provides findings that have international relevance, particularly related to place of care and introduction of EoLC discussions. The expertise and previous experience of parents is highly relevant and should be acknowledged. EoLC decision-making is a complex and nuanced process; the information needs and preferences of each family are individual and need to be understood by the professionals involved in their care. **Full text:** <http://bit.ly/2W0ckVs>

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- *JAMA NEUROLOGY* | Online – 13 May 2019 – ‘**Estimating neurologic prognosis in children: High stakes, poor data.**’ Parents of critically ill children often ask their physicians to predict their child’s future so that they can make medical decisions and plan for his or her life. The stakes can be high: some parents must decide whether to resuscitate a child if he or she deteriorates, whether to remove the ventilator in the face of brain injury, or how to balance the possibilities of death and life with future disability. Other families face less acute decisions, such as whether to relocate to a home with disability access or transition to a different type of school. The child’s prognosis – what life might look like in the future – is central to these choices. **Abstract:** <http://bit.ly/2w0gPBy>

Most GPs [in the U.K.] have too little time to discuss end-of-life care

GP | Online – 16 May 2019 – Amid rising pressure on general practice, 72% of the 370 GPs who responded to a survey by the medico-legal organisation Medical Protection said they did not have enough time to discuss end-of-life care (EoLC). The findings come just months after the Royal College of General Practitioners published quality improvement standards for EoLC in general practice, alongside research showing that four in five GPs felt that heavy workload left them unable to dedicate as much time as they would like to EoLC.¹ The Medical Protection poll also found that just 55% of GPs felt comfortable talking to patients about dying. The defence organisation said good communication around end of life issues was vital to ensure quality care, and warned that easing pressure on GPs was essential to allow time for this. <http://bit.ly/2HnyNms>

1. ‘Palliative and End-of-Life Care Toolkit,’ Royal College of General Practitioners, noted in 18 February 2019 issue of *Media Watch*, #602, p.11. **Download/view at:** <http://bit.ly/2GI2LTJ>

Diabetes in end of life care

INNOVAIT | Online – 7 May 2019 – Patients approaching the end of their lives and who have diabetes have a unique set of care needs. For patients entering their final days, a diagnosis of diabetes can raise difficult questions, exacerbate symptoms, and be an additional stress for individuals and their carers. This article aims to help readers improve the care of people with diabetes right up to their death, and summarises new guidance from Diabetes UK that offers medical practitioners support when making decisions related to diabetes management.¹ **Abstract:** <http://bit.ly/2LOHTOP>

1. ‘End of Life Diabetes Care: Clinical Care Recommendations, Diabetes UK, March 2018, noted in 9 April 2018 issue of *Media Watch*, #558, p.5. **Download/ view at:** <http://bit.ly/2Q8cYLF>

Challenging the pessimism in providing critical care for elderly patients

JAMA NETWORK OPEN, 2019;2(5):e193201. Of late, there has been a welcome shift in the end-of-life care conversation from attempting to consume fewer resources toward attempting to increase the quality of end-of-life health care.¹ Highlighting the importance of this approach, a 2006 study found that most elderly patients, when asked, preferred end-of-life care that reflects a focus on symptom and pain reduction as opposed to a technologically focused or aggressive course in the hospital and ICU.² A fundamental challenge in attempting to improve care at the end of life is the inability to know prospectively when exactly the end of life is. Two population-based studies of elderly patients admitted to a hospital or the ICU found that a somewhat surprising proportion of elderly patients not only survived critical illness but were discharged from the hospital and to independent functioning.^{3,4} **Full text:** <http://bit.ly/2Jl7dtF>

1. ‘End-of-life care, not end-of-life spending,’ *JAMA Forum*, July 2018. **Full text:** <http://bit.ly/2Hun1qH>
2. ‘What matters most in end-of-life care: Perceptions of seriously ill patients and their family members,’ *Canadian Medical Association Journal*, 2006;174(5):627-633. **Full text:** <http://bit.ly/2LIQimY>
3. ‘Long-term outcomes and health care utilization following prolonged mechanical ventilation,’ *Annals of the American Thoracic Society*, 2016;14(3):355-362. **Full text:** <http://bit.ly/2Hq9VKV>

Cont.

4. 'Recovery after critical illness in patients aged 80 years or older: A multi-center prospective observational cohort study,' *Intensive Care Medicine*, 2015;41(11):1911-1920. **Abstract (w. list of references):** <http://bit.ly/2YzLe5V>

Improving primary and specialist palliative care in cardiovascular disease

JAMA NETWORK OPEN, 2019;2(5):e192356. There are not enough palliative care (PC) specialists to see all the patients with serious cardiovascular disease (CVD) who may benefit from PC, so it is critical to develop capacity and competency in primary (i.e., basic) PC and refer appropriate patients to specialist PC teams. A 2018 randomized clinical trial examined a team-based, collaborative care approach to improve quality-of-life outcomes for patients with serious heart failure, and some patient-reported outcomes improved. Other approaches, such as the use of technology and peer support, have potential to enable patients and informal caregivers to benefit without relying on busy, complicated health systems. What aspects of primary PC are addressed by cardiology, primary care, and mental health, and how can this be improved? Roles, capacities, and competencies vary depending on the health system, clinicians, and resources available. Primary PC requires collaboration among different healthcare professionals (e.g., cardiologists, PC specialists, primary care specialists, mental health specialists, physicians, nurses, social workers, chaplains). A 2017 review proposed key primary and specialist roles in PC for patients with heart failure.¹ Leveraging the skills of affiliate healthcare professionals (e.g., nurses, social workers, chaplains) and engaging patients and caregivers using technology are approaches to improve primary PC in CVD. **Full text:** <http://bit.ly/309VhjF>

1. 'Primary palliative care for heart failure: What is it? How do we implement it?' *Heart Failure Review*, 2017;22(5):611-620. **Abstract (w. list of references):** <http://bit.ly/2LJVB5g>

Identifying palliative care champions to promote high-quality care to those with serious illness

JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 10 May 2019 – Leading medical authorities advocate for routine integration of palliative care (PC) for all major causes of death in the U.S. With rapid growth and acceptance, the field of PC is tasked with addressing a compelling question of its time: "Who will deliver timely, evidence-based PC to all who should benefit?" The current number of PC specialists will not suffice to meet the needs of persons with serious illness. In 2010, initial estimates quantified the shortage at 6,000 to 18,000 additional PC physicians needed to fully staff existing programs. Unfortunately, the predicted number of specialty physicians in 2030 will likely not be larger than the workforce in existence today. These findings result in a physician-to-serious-illness-person ratio of about 1:28 000 in 2030. To address the workforce shortage, stronger alignment is needed between intensity of patient needs and provision of PC services. Such an alignment better harnesses the talents of those in a position to deliver core PC services (such as discussing goals of care with patients or managing their symptoms) while engaging PC specialists to address more complex issues. The authors introduce the concept of "Palliative Care Champions," who sit at the nexus between specialty PC and the larger clinical workforce. Acknowledging that the needs of most patients can be met by clinicians who have received basic PC training, and that specialty PC is not always available for those with more complex needs, there exists an important opportunity for those with additional interest to scale training and quality improvement to fill this void. **Abstract:** <http://bit.ly/30fsJ8b>

Noted in Media Watch 8 April 2019 (#609, p.4):

- U.S. | *Hospice News* – 2 April 2019 – '**Congress tackles hospice and palliative care staffing shortage.**' The 'Palliative Care and Hospice Education and Training Act' would provide funds to increase the number of permanent faculty in academic institutions that train hospice and palliative care (PC) providers, with the ultimate goal of growing the workforce. Other provisions would create a national campaign to promote the benefits of palliative and hospice care among healthcare providers and the public, and would expand National Institutes of Health research efforts on hospice care. Currently the U.S. has 13.35 hospice and PC specialists for every 100,000 adults 65 and older. A 2018 study estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000.¹ <http://bit.ly/2WljvyS>

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1. 'The growing demand for hospice and palliative medicine physicians: Will the supply keep up?' *Journal of Pain & Symptom Management*, published online 2 February 2018 (noted in 16 July 2018 issue of Media Watch, #572, p.10). **Full text:** <http://bit.ly/2CRjxwO>

Planning ahead for end-of-life healthcare among Iranian American older adults: Attitudes and communication of healthcare wishes

JOURNAL OF CROSS-CULTURAL GERONTOLOGY | Online – 9 May 2019 – The purpose of this study was to examine relationships between attitudes toward planning for end-of-life (EoL) care and social supports, spirituality, distrust of the U.S. healthcare system, and acculturation; and to investigate a relationship between attitudes and communication of EoL wishes in Iranian American older adults. The participants [in this descriptive, cross-sectional study] were new immigrants to the U.S., highly educated, and insured with a generally positive self-reported health status. Of this sample, 47.4% reported that they communicated their EoL wishes orally or through written documentation. Favorable attitudes toward planning were associated with acculturation and healthcare system distrust, and, inversely, were negatively associated with spirituality. No significant association was found between attitudes and social support. Favorable attitudes predicted participants' communication of wishes. These findings can inform the provision of effective interventions to enhance culturally competent EoL care. **Abstract (w. list of references):** <http://bit.ly/2HeqNFx>

Noted in Media Watch 4 March 2019 (#604, p.15):

- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 22 February 2019 – '**Preferences regarding and communication about end-of-life care among older Iranian-American adults.**' The results of this study showed about half of the 130 participants had communicated their end-of-life care preferences through written documents and/or verbal discussions. A set of factors predicted the preferences and communications. Higher scores of social support and greater numbers of cohabitants were associated with a preference for home care, and experience of a loved one's death was associated with participants being willing to communicate their preferences for type of care. **Abstract:** <http://bit.ly/2XnALuz>

A survey of hospice professionals regarding medical cannabis practices

JOURNAL OF PALLIATIVE MEDICINE | Online – 16 May 2019 – With medical cannabis (MC) remaining illegal at the federal level [in the U.S.], hospice programs are unsure how to handle requests for MC, particularly since hospice is largely funded with federal dollars. Three hundred ten hospice professionals responded to an anonymous online survey. More than half of the respondents were nurses followed by administrators and physicians. Regardless of legal status, hospice staff members were overwhelmingly in agreement that MC is appropriate for hospice patients to have access to and use. Several barriers to use were identified including discordant legal status between state and federal governments, concerns about clinical efficacy and safety, and a myriad of other societal factors. Wide variations in MC documentation and education practices between hospices were noted. The data suggest overwhelming support for MC use in the hospice setting. **Abstract:** <http://bit.ly/2JMncAg>

N.B. Additional articles on cannabinoids in palliative medicine noted in 29 April 2019 issue of Media Watch, #612, p.9, including the special issue of the *Journal of Palliative Medicine* on the topic.

Using nurse care managers trained in the serious illness conversation guide to increase goals-of-care conversations in an accountable care organization

JOURNAL OF PALLIATIVE MEDICINE | Online – 13 May 2019 – The authors undertook a project to increase the number of serious illness conversations occurring in an accountable care organization (ACO) using a script delivered telephonically by nurse care managers. After testing and modifying the script, they imbedded it into the initial nursing assessment in the electronic medical record. The electronic medical record prompts the nurses to ask the questions every three months to track changes in goals of care over time. This project increased documentation of goals-of-care conversations from 33% of patients in the sub-population during the first month of this project to 86% at the end of the first year. Nurse care managers' report that clinical outcomes are improved by these conversations. This project demonstrates a unique way to modify the Serious Illness Conversation Guide for use by nurses as part of a healthcare team. This project can be adapted by other healthcare organizations trying to increase goals-of-care conversations in their patient population. **Abstract:** <http://bit.ly/2vXGnze>

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 14 May 2019 – ‘Goals-of-care decisions by hospitalized patients with advanced cancer: Missed clinician opportunities for facilitating shared decision-making.’ In this qualitative study, clinicians' approach to decision-making included: “information exchange,” “deliberation,” “making a patient-centered recommendation,” and “wrap-up: decisional status.” When discussing code status, clinicians missed opportunities to engage patients in information exchange and to wrap up decisional status. In contrast, clinicians discussing disease-modifying treatments and hospice failed to integrate patient preferences. Clinicians also missed opportunities to make patient-centered recommendations when discussing treatment decisions. **Abstract (w. link to references):** <http://bit.ly/30nssQD>

College palliative care volunteers: Too early to feed the pipeline for palliative care clinicians?

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 May 2019 – The University of Iowa Hospitals & Clinics has a palliative care (PC) volunteering program that has recruited college students since 2010. There is little research on the effects of PC volunteering on collegiate volunteers. Seventy-one percent of survey respondents reported they were more likely to pursue PC after volunteering. PC volunteering helped change views of patient care and abilities to discuss end-of-life situations. Ninety-one percent served as informal ambassadors by discussing PC with family and peers. Major themes identified include motivation to volunteer for patient contact and interest in learning about PC. Respondents described meaningful patient interactions, lessons in empathy, and the power of listening. These results suggest that PC volunteering affects career choices and helps volunteers gain needed listening skills for patient care in the future. The unique exposure and interactions with PC patients and their families have changed volunteers' understanding of healthcare. PC volunteers speak in their social networks about PC. This experience may increase the likelihood of student volunteers to pursue careers in PC. **Abstract:** <http://bit.ly/2WBS8eQ>



Attitudes and perceptions of paramedics about end-of-life care: A literature review

JOURNAL OF PARAMEDIC PRACTICE | Online – 7 May 2019 – Involvement with end-of-life care is the context in which this paper examines how paramedics perceive and respond to this part of their role. Five themes emerged, which suggest that paramedics are not prepared to work with crisis situations involving the end of patients' lives: 1) Emotional resilience; 2) Decision making; 3) Communicating death; 4) Recognising dying patients; and, 5) Death education. The review concludes that the dearth of data is not preventing improvements in services, nor education and training, in this field. **Abstract:** <http://bit.ly/2YtgYcV>

N.B. Articles on paramedics and end-of-life care noted in past issues of Media Watch – in Canada 18 February 2019, #602, p.9; in Australia 11 February 2019, #601, p.12; and, in the U.K. 20 August 2018, #577, p.7.

A perfect storm: Fear of litigation for end-of-life care

MEDICAL JOURNAL OF AUSTRALIA | Online – 8 May 2019 – Healthcare at the end of life (EoL) has been significantly disturbed by two converging fronts. The first is very public conversations relating to opioid overuse. The second is the current tension between standard EoL care and voluntary assisted suicide. The top 20% of opioid prescribers in Australia – including almost 5,000 general practitioners – were recently sent letters warning them that their clinical practice was being scrutinised. This warning was an attempt to arrest an increasing number of deaths caused by overuse of prescription opioids. An unintended but predictable consequence appears to have arisen: anecdotal reports of some practitioners choosing to abandon EoL care altogether rather than risk professional ruin should they persist in the use of any opioid therapy. While this is still anecdotal information, when added to an overcautious attitude towards prescribing higher dose opioids among some medical practitioners even when it is clinically warranted, the consequences for patient care could be serious. Treatment of chronic pain with long term opioids and opioid use at the EoL are two different issues. The National Pain Strategy emphasises the importance of a multimodal approach to chronic pain, highlighting the need of learning to live effectively with pain but not withholding opioids should they be necessary. In many patients, long term opioid use is appropriate, allowing a normal and productive life. For others, prolonged high dose opioid is used in isolation from other treatment modalities. In palliative care, opioid use is usually limited to the final months of life and is therefore unlikely to lead to the same problems that can arise in chronic pain practice. Tolerance and dose escalation are of almost no consequence because the intent is time-limited symptom control. The second storm front is assisted suicide. **Access article at:** <http://bit.ly/2E4fCNX>

N.B. Additional articles on opioid use in the context of palliative and EoL care noted in 28 January 2019 and 31 December 2018 issues of Media Watch, #599, p.10 and #595, pp.5,19, respectively.

Noted in Media Watch 17 September 2018 (#581, p.8):

- *JOURNAL OF PAIN & PALLIATIVE CARE PHARMACOTHERAPY* | Online – 10 September 2018 – ‘**Ensuring and restoring balance on access to controlled substances for medical and scientific purposes: Joint statement from palliative care organizations.**’ The central principle of “balance” represents the dual obligation of governments to establish a system of control that ensures the adequate availability of controlled substances for medical and scientific purposes while simultaneously preventing their non-medical use, diversion, and trafficking, two primary goals of the international control system. **Abstract:** <http://bit.ly/2O90DWx>

Palliative care for people with dementia living at home: A systematic review of interventions

PALLIATIVE MEDICINE | Online – 6 May 2019 – This review offers evidence on palliative care (PC) interventions for people with dementia living at home and highlights the paucity of high-quality studies in this area. It emphasises the need for more rigorous and comprehensive research which considers the identified gaps in the evidence and addresses the specific issues and challenges that dying at home with or from dementia poses. The European Association for Palliative Care’s definition of optimal PC in dementia provided a useful framework for a systematic assessment of the range and focus of evidence of what is effective for people with dementia living and dying at home.¹ **Full text:** <http://bit.ly/30cjk1e>

1. ‘White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,’ *Palliative Medicine*, published online 4 July 2013 (noted in 8 July 2013 issue of Media Watch, #313, p.10). Full text: <http://bit.ly/2JfbRcs>

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Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing begging on p.19.

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 May 2019 – ‘**Before hospice: Symptom burden, dementia, and social participation in the last year of life.**’ In this cross-sectional logistic regression analysis of a population-based study, decedents with dementia (37.3%) had higher prevalence of all symptoms, except insomnia and breathing problems. Dementia was associated with greater likelihood of high versus low burden of sensory, physical, and psychiatric symptoms. Dementia and physical symptoms (problems with speaking, leg strength/movement, and balance) were independently associated with limitations in at least three social activities. **Abstract:** <http://bit.ly/2VTHn5J>

N.B. Additional articles on PC for people living with Alzheimer’s and other forms of dementia noted in 22 April 2019 issue of Media Watch, #611, p.9.

Palliative care training for work in an austere environment after a natural disaster

PREHOSPITAL & DISASTER MEDICINE | Online – 6 May 2019 – Challenges to the care of the dying during a disaster include a loss of medical infrastructure and scarce medical or physical resources. Palliative care (PC) training for non-PC specialists can be instructive for the development of PC training for medical care responders after disasters. Applying standards, identifying goals-of-care for the expectant patient, communication to the patient and family members, if available, can help reduce suffering of this group of devastatingly vulnerable patients. In addition, peer support, on-site discussions and debriefing, and problem-solving when resources are limited will help alleviate moral distress among the providers. **Abstract:** <http://bit.ly/2HeVGIY>

N.B. Additional article on integrating PC and symptom relief into responses to humanitarian emergencies and crises noted in 14 January 2019, #597, p.5.

Preferences for place of care and place of death: What, how, when and who to ask?

PROGRESS IN PALLIATIVE CARE | Online – 5 May 2019 – As healthcare systems worldwide are confronted with increasing numbers of aging patients and those living with life-limiting illnesses, the topic of where people want to spend their last days has received considerable attention. However, the strategies that researchers and clinicians use to capture these end-of-life (EoL) views vary greatly in four key questions. These include: what, how, when and who to ask about location preferences. The authors argue that how researchers and clinicians choose to answer these questions directly influences their findings. Based on these considerations, they highlight ways to improve future palliative care and empirical EoL studies by addressing the precision, methods, timing and sources of preference assessments. Only when we are able to accurately identify where people want to spend their last days, can we begin to meet the needs of patients as they approach the final stage of their lives. **Abstract:** <http://bit.ly/2HcePw9>

Related

- *INTERNATIONAL JOURNAL OF HEALTH GEOGRAPHICS* | Online – 6 May 2019 – ‘**Urban and rural differences in geographical accessibility to inpatient palliative and end-of-life care facilities and place of death: A national population-based study in England, U.K.**’ Rural dwellers are less likely to die at palliative and end-of-life (EoL) care inpatient facilities, compared to their urban counterparts. The findings of this study can feed into local EoL policies and strategies of other countries to improve equity in healthcare delivery for people nearing EoL. The utility of individual-level death data as a unit of analysing geographic access permitted a detailed examination of urban/rural differences in the association between geographic access to inpatient palliative and EoL care and place of death. **Abstract:** <http://bit.ly/2VpPJ5l>

Psychosocial interventions for advanced cancer patients: A systematic review

PSYCHO-ONCOLOGY | Online – 11 May 2019 – Psychosocial care for advanced cancer encompasses a wide range of interventions that help patients make life-changing decisions, manage debilitating symptoms, confront impending mortality, and improve other patient outcomes. Psychosocial care is becoming increasingly available to advanced cancer patients; however, an overview of the various types of interventions is lacking. The authors found a range of psychosocial interventions studies and grouped them based on six theoretical/clinical approaches: 1) Cognitive behavioural therapy-based; 2) Meaning-enhancing; 3) Dignity, life review, and narrative; 4) Other counselling; 5) Education-only; and, 6) Music, writing and others. The different interventions had significantly varied characteristics (e.g., format, duration, and resources used) to address issues faced by advanced cancer patients. There is compelling evidence for the use of meaning-centred psychotherapy to improve meaning and quality of life, and use of question prompt lists and communication skills training to improve communication with healthcare providers. Some psychosocial interventions are further along in establishing evidence for effectiveness. The findings of this review demonstrate a growing capacity within the field to meet the psychosocial needs of advanced cancer patients. Lessons and direction in clinical practice and future research endeavours are discussed. **Abstract:** <http://bit.ly/30bJstc>

An early palliative care intervention can be confronting but reassuring: A qualitative study on the experiences of patients with advanced cancer

PALLIATIVE MEDICINE | Online – 9 May 2019 – Intervention trials confirm that patients with advanced cancer receiving early palliative care (PC) experience a better quality of life and show improved knowledge about and use of PC services. To involve patients in future healthcare decisions, health professionals should understand patients' perspectives. However, little is known about how patients' experience such interventions. Participants in this study received the intervention well and gained a better understanding of their personal situation. Patients reported that the intervention can feel "confronting" but with the right timing it can be confirming and facilitate family conversations. Patients' personal background and the intervention timing within their personal disease trajectory influenced their emotional and cognitive experiences; it also impacted their understanding of PC and triggered actions toward future care planning. Early PC interventions like 'Symptoms, End-of-life (EoL) decisions, Network, Support' may provoke emotions and feel "confrontational" often because this is the first time when issues about one's EoL are openly discussed; yet, advanced cancer patients found it beneficial and felt it should be incorporated into routine care. **Abstract:** <http://bit.ly/2PZPRD5>

Noted in Media Watch 21 January 2019 (#598, p.13):

- *PALLIATIVE MEDICINE* | Online – 16 January 2019 – '**Brief psychosocial interventions improve quality of life of patients receiving palliative care: A systematic review and meta-analysis.**' Fifteen studies met the eligibility criteria and reported the effects of 17 interventions and a total of 1,248 patients. The most frequently used techniques were life review techniques and music therapy. After exclusion of outliers, psychosocial interventions showed to be superior with regard to the improvement of quality of life, and the reduction of emotional and existential distress compared to the control groups. **Abstract:** <http://bit.ly/2VwMBFr>

Noted in Media Watch 22 October 2018 (#586, p.5):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 16 October 2018 – '**Development of a tool to identify and assess psychosocial and spiritual needs in end-of-life patients.**' The Psychosocial & Spiritual Needs Evaluation scale was developed through a 7-stage process: 1) Literature review; 2) Expert panel establishment; 3) Discussion and agreement on the most relevant dimensions of psychosocial care; 4) Description of key indicators and consensus-based questions to evaluate such dimensions; 5) Assessment of the scale by palliative care professionals; 6) Evaluation by patients; and, 7) Analysis of scale's psychometrics properties. **Abstract (w. list of references):** <http://bit.ly/2Ckr8DM>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BIOLAW JOURNAL* | Online – 9 May 2019 – ‘**Voluntary euthanasia, assisted suicide and law reform: A sketch of the Canadian experience.**’ The author outlines the recent Canadian experience of replacing the blanket prohibition of assisted suicide and voluntary euthanasia with a new regulatory regime for “medical assistance in dying” (MAiD). The aim is to illustrate how lawmakers in Canada have pursued the project that the Italian Constitutional Court has urged Italy’s parliament to undertake. The author traces the arguments behind this law reform, highlighting ongoing disagreements over the manner in which it reconciles the protection of constitutional rights and the pursuit of particular policy objectives. Of course, the constitutional structures, political dynamics, medical cultures, and legal systems of these two countries differ in potentially salient ways. This article is not a case for substituting Canada’s MAiD regime for Italy’s current end-of-life laws whole cloth. Instead, the goal is to signal ways of thinking about, and responding to, some of the more pressing and difficult challenges to which efforts at law reform in this area may give rise. **Abstract:** <http://bit.ly/2Q2Lt6h>
- *BMC MEDICAL ETHICS* | Online – 14 May 2019 – ‘**A qualitative study on existential suffering and assisted suicide in Switzerland.**’ Representations by the palliative care and primary care providers and volunteers from EXIT on existential suffering are multiple. They include the notion of physical decline and its consequences, loneliness, fear of the future, life is over, loss of social significance, loss of hope for a better future, being a financial burden and loss of pleasurable activities. To the authors’ knowledge, no study had been conducted yet on the perspectives of these people in a country like Switzerland, where assisted suicide (AS) is legal and where different groups of people have to confront it and try to respond to it. This study might be helpful in providing a better understanding of existential suffering to and help identify a wider range of alternatives to offer these suffering people, rather than simply thinking of limiting the conditions for an acceptable AS. **Full text:** <http://bit.ly/30iJb7V>
- *BMJ JOURNAL OF MEDICAL ETHICS* | Online – 15 May 2019 – ‘**Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners.**’ The majority of Dutch physicians feel pressure when dealing with a request for euthanasia or physician-assisted suicide (EAS). This study aimed to explore the content of this pressure as experienced by general practitioners. Six categories of pressure ... were revealed: 1) Emotional blackmail; 2) Control and direction by others; 3) Doubts about fulfilling the criteria; 4) Counter-pressure by patient’s relatives; 5) Time pressure around referred patients; and, 6) Organisational pressure. The authors conclude that the pressure can be attributable to the patient-physician relationship and/or the relationship between the physician and the patient’s relative(s), the inherent complexity of the decision itself, and the circumstances under which the decision has to be made. **Abstract:** <http://bit.ly/2Q8c1Dc>
- *DEATH STUDIES* | Online – 15 May 2019 – ‘**Suicide vs. medical assistance in dying (MAiD): A secondary qualitative analysis.**’ This is a secondary analysis of three qualitative studies about MAiD in which researchers asked about the differences between suicide and MAiD. In all, researchers interviewed 52 Canadians; 7 were people who had requested MAiD and had been found ineligible, 6 were MAiD providers and 39 were socially and economically marginalized. The overwhelming response was that MAiD is better than suicide in the context of suffering at the end of life. Whereas these people perceived suicide as uncertain, difficult, and something that was usually done alone and without support, they thought MAiD was certain, painless, and more socially acceptable. **Abstract:** <http://bit.ly/2Q7d9H3>
- *POLICY, POLITICS & NURSING PRACTICE* | Online – 6 May 2019 – ‘**Medical assistance in dying: A review of Canadian nursing regulatory documents.**’ Canada’s legalization of Medical Assistance in Dying (MAiD) in 2016 has had important implications for nursing regulators. Evidence indicates that registered nurses perform key roles in ensuring high-quality care for patients receiving MAiD. Further, Canada is the first country to recognize nurse practitioners as MAiD assessors and providers. The purpose of this article is to analyze the documents created by Canadian nursing regulatory bodies to support registered nurse and nurse practitioner practice in the political context of MAiD. A search of Canadian provincial and territorial websites retrieved 17 documents that provided regulatory guidance for registered nurses and nurse practitioners related to MAiD. Responsibilities of registered nurses varied across all documents reviewed but included assisting in assessment of patient competency, providing information about MAiD to patients and families, coordinating the MAiD process, preparing equipment

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and intravenous access for medication delivery, coordinating and informing healthcare personnel related to the MAiD procedure, documenting nursing care provided, supporting patients and significant others, and providing post death care. Responsibilities of nurse practitioners were identified in relation to existing legislation. Safety concerns cited in these documents related to ensuring that nurses understood their boundaries in relation to counseling versus informing, administering versus aiding, ensuring safeguards were met, obtaining informed consent, and documenting. Guidance related to conscientious objection figured prominently across documents. These findings have important implications for system level support for the nursing role in MAiD including ongoing education and support for nurses' moral decision making. **Abstract:** <http://bit.ly/2VeJvkf>

Publishing Matters

Academics raise concerns about predatory journals on PubMed

THE SCIENTIST | Online – 9 May 2019 – PubMed, the National Library of Medicine's repository of millions of abstracts and citations, has long been one of the most highly regarded sources for searching biomedical literature. For some members of the scientific community, the presence of predatory journals – publications that tend to churn out low-quality content and engage in unethical publishing practices – has been a pressing concern. To understand how predatory journals might get into PubMed, it's important to first recognize the database's components. PubMed was originally created in 1996 as a public interface to MEDLINE, the National Library of Medicine's (NLM's) database of citations and abstracts from selected journals in the medical and the life sciences. While MEDLINE references still make up a majority of articles on PubMed, the second-largest chunk of listed papers now comes from PubMed Central (PMC), an online, freely-accessible archive of articles from journals and publishers with agreements with the NLM, manuscripts from authors complying with funders' open-access policies, and historical content archived by digitization projects. Both MEDLINE and PMC have quality-control measures in place. MEDLINE has a long-standing, rigorous selection process, through which a federal advisory committee conducts a thorough evaluation of journals, examining things such as their publishing practices and the scientific merit of their contents. Journals that are accepted into PMC go through a similar – but more recently implemented – appraisal process. Accepted manuscripts, however, are deposited into PMC without review. **Full text:** <http://bit.ly/2PZjRz3>



Noted in Media Watch 10 September 2018 (#580, p.12):

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2018;190(35):E1042-E1045. '**How predatory journals leak into PubMed.**' PubMed handles millions of queries daily and represents a key source of knowledge for health researchers worldwide. Much medical research that underpins clinical practice relies on the findings generated by peer-reviewed studies that are retrieved via biomedical databases, in particular, those that are free to search such as MEDLINE and PubMed. Thus, it is imperative that these databases are free of contamination by the outputs of predatory journals with their critically flawed peer review procedures. The authors analyze why this is happening and identify some possible solutions to stop the penetration of predatory journals and publishers into biomedical databases. **Access options:** <http://bit.ly/2Jggl2M>

N.B. See 'RE: How predatory journals leak into PubMed,' *Canadian Medical Association Journal*, published online 10 December 2018 (noted in 17 December 2018 issue of Media Watch, #594, p.13): **Full text:** <http://bit.ly/30dEhsU>



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International



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