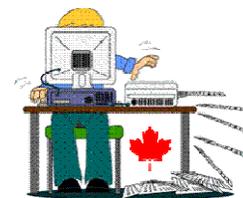


Media Watch...

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

Hospice support for non-cancer patients with a deteriorating health trajectory needs to precede patient and family recognition that end-of-life care is needed.

'A review of the literature on family decision-making at end of life precipitating hospital admission,' (p.9), in *British Journal of Nursing*.

Canada

More than half of people served by Maamwesying will never live to see retirement, says new report

ONTARIO | *Soo Today* (Sault Ste Marie) – 18 July 2019 – Maamwesying North Shore Community Health Services says that more than half of registered members of First Nations along Lake Huron's north shore that are served by the health organization never live to see retirement, and tend to die at younger ages than the rest of Ontario. That's just a couple of the findings revealed by the health organization in its report, 'Learning from Our Ancestors: Mortality Experience of Communities Served by Maamwesying North Shore Community Health Services.' The report ... is the result of two years' worth of work, using data collected from a number of sources, including Ontario Health Insurance Plan, death certificates, and the Indian Registry System between 1992 and 2014. Some of the findings include: 53% of community members die before age 65 compared to 22% for Ontario overall; Mortality rates due to circulatory deaths are 20% higher (1.2 times higher) than the Ontario average; and, 22% of community members have a history of kidney failure, compared to 17% for Ontario as a whole. The Maamwesying mortality report is part of a larger study on mortality rates that pooled data from 59 First Nations

in northern Ontario in partnership with nine other regional tribal councils and health organizations. <http://bit.ly/2LvsHVF>

N.B. Link to the Maamwesying report embedded in the *Soo Today* article.

Medicare and the care of First Nations, Métis and Inuit

HEALTH ECONOMICS, POLICY & LAW | Online – 1 February 2018 – The Canada Health Act is silent on its relationship to the Indigenous healthcare system. The Act has not kept pace with Indigenous self-government activities that have spread across Canada. It has unfortunately crystallized the federal/provincial/territorial/Indigenous jurisdictional fragmentation that perpetuates health inequities and has failed to clarify these jurisdictions' obligations towards Indigenous peoples. **Abstract (w. list of references):** <https://goo.gl/Wqexyx>

N.B. This article was noted in 5 February 2018 issue of Media Watch (#549, p.10). Selected articles on palliative and end-of-life care for the Indigenous peoples of Canada noted in 24 June 2019 and 3 September 2018 issues of Media Watch (#619, p.6 and #579, p.12, respectively.)

U.S.A.

New law allows medication to be easily adjusted during end-of-life care

MICHIGAN | WLEN Radio (Adrian) – 19 July 2019 – A new law ... allows hospice providers to easily adjust pain medication so they can provide dignified end-of-life care to patients. Reforms were needed after a state law enacted in 2018 to combat the opioid epidemic inadvertently made it harder for hospice providers to administer pain medication. Because most hospice care is provided in the patient's home ... personal visits from a prescriber are difficult – and sometimes impossible – during a crisis situation. House Bill 4225, now Public Act 43 of 2019, allows hospice care providers to administer pain medications to hospice patients without delay.

They will no longer be required to obtain and review a report from the Michigan Automated Prescription System or establish a “*bona fide* prescriber-patient relationship” before administering medication. <http://bit.ly/2Y3zVIB>

Specialist Publications

'Palliative care consultation is underutilized in critically ill general surgery patients' (p.5), in *American Journal of Hospice & Palliative Medicine*.

House Ways & Means starts Rural Health Task Force

HOSPICE NEWS | Online – 18 July 2019 – The influential Ways & Means Committee within the U.S. House of Representatives has convened a Rural & Underserved Communities Health Task Force to consider health care delivery challenges in rural areas. The move comes as both chambers of Congress consider versions of legislation to expand hospice in rural locales. If enacted, the Rural Access to Hospice Act would remove a statutory barrier to hospice utilization in rural communities by allowing physicians in Rural Health Centers and Federal Qualified Health Centers to serve as attending physicians for patients in hospice. Both types of centers would be able to bill Medicare for hospice attending physicians services, which the law currently prohibits. Rural families have less access to hospice care programs than people in more concentrated populations, according to a 2015 study.¹ Rural counties are less likely to have a Medicare-certified hospice than urban counties, and the service area of the nearest hospices may not extend far enough to reach some rural patients. Challenges delivering hospice care for rural programs include geography, resources, and staff education and retention. Geographical challenges in rural areas consist of unpredictable access to patient homes due to weather, topographical features, poorly maintained roads, and long distances between homes, the study found. <http://bit.ly/2XOa71a>

1. 'Quality of hospice care: Comparison between rural and urban residents,' *Journal of Nursing Care Quality*, published online 26 December 2014. [Noted in 5 January 2015 issue of *Media Watch* (#391, p.6)] **Full text:** <http://bit.ly/2LsDBM9>

N.B. Additional articles on the provision and delivery of hospice and palliative care services in rural America noted in 4 March 2019 issue of *Media Watch* (#604, p.7).



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/2RMIImQK>

Man died after Orlando legal guardian filed “do not resuscitate” order against his wishes, investigation finds

FLORIDA | *The Orlando Sentinel* – 15 July 2019 – 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. Thorpe found Fierle had “abused her powers” by requesting that incapacitated clients not receive medical treatment if their

heart or breathing stopped – without permission from their families or the court, records show. Guardians are court-appointed decision-makers for minors and adults with mental and physical disabilities, known as wards. <http://bit.ly/2XPRIIj>

[Specialist Publications](#)

‘End-of-life decision making and treatment for patients with professional guardians’ (p.11), in *Journal of the American Geriatrics Society*.

The big number: 20 million caregivers perform complex medical and nursing tasks

THE WASHINGTON POST | Online – 14 July 2019 – About 20 million U.S. residents – half of those who care for friends or family members at home – perform complex medical and nursing tasks for the people in their care. This means that family caregivers are doing tasks typically done by healthcare professionals, such as giving injections, managing tube feedings and dealing with medical equipment, often for people with multiple conditions, according to a report from the Home Alone Alliance...¹ About 82% of these caregivers manage medications, 51% help with mobility devices, 48% prepare special diets, 37% administer wound care, and 30% manage incontinence. Seven of every 10 home-caregivers help someone manage chronic pain, which the report says increases the stress and worry that caregivers face, especially in the midst of the country’s opioid epidemic. <https://wapo.st/2JCcBYt>

1. ‘Home Alone Revisited: Family Caregivers Providing Complex Care,’ Home Alone alliance, July 2019. **Download/view at:** <http://bit.ly/2UyvRli>

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

- *MEDSCAPE* | Online – 13 February 2019 – ‘**Dying at home: The burden of medication management.**’ A recent literature review explored the experiences and perspectives of family caregivers in managing medications for a family member being cared for and dying at home.¹ The authors reviewed 15 studies in this area and synthesized the findings into five key themes that provide a framework to improve support for these caregivers: These concepts provide important perspectives on caregiver fears, such as over-medicating the patient, and challenges in understanding instructions, particularly with multiple medications. **Full text:** <https://wb.md/2X43MeD>

1. ‘Managing medicines for patients dying at home: A review of family caregivers’ experiences.,’ *Journal of Pain & Symptom Management*, published online 11 September 2018. [Noted in 17 September 2018 issue of Media Watch (#581, p.12)] **Full text:** <http://bit.ly/2tli8t8>

[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/2RPy9b>



International

Zoe's Place warn children's hospices "at crisis point" due to lack of funding

U.K. (England) | *The Northern Echo* (Darlington) – 16 July 2019 – Bosses of a cash-strapped baby hospice have warned more children's hospices could be forced to reduce their services to families in need even further unless there is a significant increase in funding. Joan Stainsby, the executive trustee at Zoe's Place Baby Hospice, said the lack of funding from the National Health Service (NHS) and local government has now reached "crisis point." Last week, NHS England pledged to ring fence funding to children's hospices by 2023, but over the last three years more than 60% of children's hospices, including Zoe's Place, have had to use reserves to cover the shortfall in income, according to Mrs. Stainsby. The warning comes after the Middlesbrough-based hospice warned they were in the "most challenging times" they'd ever faced and would be forced to close for two nights a week due to financial hardship, meaning they would be unable to offer emergency respite for families. <http://bit.ly/2xQKPQW>

Noted in Media Watch 8 July 2019 (621, p.3):

- U.K. (England) | Third Sector (Twickenham) – 2 July 2019 – **'Charity succeeds in battle to ring-fence National Health Service funding for children's hospices.'** NHS England promised last year that funding for children's hospices would more than double from £12 million to £25 million by 2023-2024, dependent on clinical commissioning groups providing additional match funding to the government's £7 million investment. But Together for Short Lives last month accused NHS England of renegeing on its promise to properly fund children's hospices by making the money available to non-palliative care, too. Following Together for Short Lives' intervention, NHS England said it would provide the full £25 million itself without input from Clinical Commissioning Groups. <http://bit.ly/2NtiZoM>

N.B. Recent news media coverage on funding children's hospices in England noted in this issue of Media Watch.

WHO: Pain management guidelines

IAHPC's response to a U.S. House of Representatives report and WHO's reaction to it

INTERNATIONAL ASSOCIATION OF HOSPICE & PALLIATIVE CARE (IAHPC) | Online – Accessed 15 July 2019 – On the 22 May 2019, two members of the U.S. House of Representatives, published a report claiming (falsely) that the development of two World Health Organization (WHO) guidance documents ('Ensuring Balance in National Policies on Controlled Substances' and 'Guidelines on the Pharmacological treatment of Persisting Pain in Children with Medical Illnesses,' was influenced by the interests of Purdue Pharma, through corrupted organizations and individuals serving the interests of that company. Among the organizations and individuals named in this report are the IAHPC, the International Children's Palliative Care Network, the European Association for Palliative Care



Specialist Publications

'Exploring the gender dimension of problems and needs of patients receiving specialist palliative care in a German palliative care unit: The perspectives of patients and healthcare professionals' (p.7), in *BMC Palliative Care*.

'Agreement with consensus statements on end-of-life care: A description of variability at the level of the provider, hospital, and country' (p.10), in *Critical Care Medicine*.

'Commonalities and differences in legal euthanasia and physician-assisted suicide in three countries: A population-level comparison' (p.14), in *International Journal of Public Health*.

Cont.

and others. The two U.S. Representatives argue that by developing, distributing, and promoting these guidelines, the WHO was helping the pharmaceutical company increase its global market share, putting other countries at risk of replicating the U.S. “opioid crisis.” No staff member of the offices of the U.S. representatives contacted any of us to verify or confirm the claims in their report before publishing it. On 19 June, WHO Director-General Dr. Tedros Adhanom Ghebreyesus sent a letter to the two U.S. Representatives informing them that the WHO had taken the concerns raised by the report “very seriously,” and that the agency had decided to “discontinue” and “update” the two guidelines. The WHO has now issued a statement on its website.¹ The WHO response took all the academic and civil society experts and organizations involved in the development of these now discontinued guidelines by surprise. It also shocked the professional associations, institutions, and government representatives who have used and applied these guidance documents to improve access for patients with medical needs. Both documents were developed in order to improve the situation of millions in the world who suffer from inadequate access to appropriate medications, including pain medications. The guidelines were not commercially initiated, funded, or influenced. <http://bit.ly/2NXciLZ>

1. ‘Web statement on pain management guidance,’ World Health Organization, July 2019. **Download/view at:** <http://bit.ly/2xLJevN>

Fear as millions of old age pensioners at risk from carers with no training: Chaos of our care system

U.K. | *The Daily Express* (London) – 15 July 2019 – Millions of old age pensioners in need of care are at the mercy of an unlicensed and unskilled workforce, a damning inquiry has found. Experts fear as many as 500,000 people pass themselves off as trained care workers after advertising their services online. Many professional care workers and providers offer excellent services but experts are worried at a growing number in a “grey area” who have no training or qualifications and work cash in hand. Disturbing new evidence suggests an increasing number are easily able to find work because the industry is unregulated. It means the vulnerable with complex health needs, many living at home, are wide open to abuse. The shocking findings have prompted the All-Party Parliamentary Group on Social Care to launch an urgent investigation. <http://bit.ly/2XljDU8>

Specialist Publications

Palliative care consultation is underutilized in critically ill general surgery patients

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 17 July 2019 – The American College of Surgeons recommends palliative care (PC) and surgeons collaborate on the care of patients with poor prognoses.¹ These collaborations are done to discuss symptom management and goals of care. However, contemporary practice patterns of PC consultation for surgical patients are poorly defined. Of the 105 patients identified [i.e., patient population studied], 6 died on the day of admission, and 39 (37%) received PC consultation. The authors’ data showed that patients who received consultation were generally older, white, and insured. Median number of days between palliative consult and death was 3 days... Goals-of-care con-

versations were the indication for consultation in 62.5% of patients. The proposed plan by the consultants was congruent with the primary team in 66.7% of cases. When PC is consulted, the plan of the primary surgical team and the palliative team align. Identification of barriers to consultation and promotion of the benefits of PC among surgical teams is warranted. **Abstract:** <http://bit.ly/2Lsrr5D>

Publishing Matters

‘Fixing health care’s replication crisis is important for researchers and patients’ (p.14), in *Stat*.

1. ‘Statement of Principles of Palliative Care,’ American College of Surgeons, August 2005. **Download/view at:** <http://bit.ly/2NXJ1jZ>

Cont.

Noted in Media Watch 11 December 2017 (#542, p.13):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 5 December 2017 – ‘**Characterizing the role of U.S. surgeons in the provision of palliative care: A systematic review and mixed-methods meta-synthesis.**’ Four major themes affected receipt of palliative care (PC) for surgical patients: 1) Surgeon experience and knowledge; 2) Surgeons’ attitudes; 3) Surgeons’ preferences and decision-making for treatment; and, 4) Perceived barriers. Surgeons overall demonstrated insight into the benefits of PC, but reported limited knowledge and comfort as well as a multitude of challenges to introducing PC to their patients. **Full text:** <http://bit.ly/2Y9K5FC>

The advance care planning nurse-facilitator: Describing the role and identifying factors associated with successful implementation

AUSTRALIAN JOURNAL OF PRIMARY HEALTH | Online – 11 July 2019 – This qualitative study appraised the components of an advance care planning (ACP) facilitator intervention comprising nurse-led patient screening and ACP discussions, and factors associated with the successful implementation of this model in primary care and acute hospital settings across rural and metropolitan Western Australia. Interview data identified factors associated with successful implementation, including patient and health professional factors, ACP facilitator characteristics, and the optimal settings for the intervention. The primary care setting was seen as most appropriate and time limitations were a key consideration. Factors associated with successful implementation included trusting relationships between the nurse-facilitator and referring doctor, and opportunities for meaningful encounters with patients. A model of ACP nurse-facilitation based in primary care may be an acceptable and

effective method of increasing ACP uptake. **Abstract:** <http://bit.ly/2Gfgtfw>

A systematic review of the effects of advance care planning facilitators training programs

BMC HEALTH SERVICES RESEARCH | Online – 7 June 2019 – This systematic review found that training for healthcare professionals in advance care planning (ACP) had positive effects on their knowledge, attitude and skills. However, there is a lack of high quality randomized controlled trials to evaluate the effectiveness of ACP facilitator training programs for nurses working in non-palliative care hospital settings. By evaluating the effectiveness of the training programs, the possibilities of such programs in clinical practice are explored and recommendations for further development of ACP training program made. **Full text:** <http://bit.ly/2WW70U2>

N.B. Noted in Media Watch 17 June 2019 (#618, p.7).

Related

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 16 July 2019 – ‘**Attitudes toward advance care planning among persons with dementia and their caregivers.**’ 431 racially diverse caregivers of persons with dementia from 13 geographically dispersed Alzheimer’s Disease Centers across the U.S. participated in a survey, ‘Care Planning for Individuals with Dementia.’ The respondents were knowledgeable about dementia and hospice care, indicated the person with dementia would want comfort care at the end stage of illness, and reported high levels of both legal advance care planning (ACP) and informal ACP discussions for the person with dementia. However, notable racial differences were present. **Abstract (w. list of references):** <http://bit.ly/2Gg7FpL>
- *JOURNAL OF AGING & HEALTH* | Online – 15 July 2019 – ‘**Feasibility of advance care planning in primary care for homeless adults.**’ The authors implemented an advance care planning (ACP) project to discuss and document advance care plans with all patients aged 45 and older who received primary care at their adult homeless program clinics. Over 14 months, ACP was discussed with 48% of the population and healthcare proxy (HCP) appointment with 91% of these patients. Most appointed a HCP from personal relationships, though a significant minority could not and were considered “surrogate-less.” End-of-life preferences varied. Approximately 20% of patients wanted to defer to a surrogate for each decision. **Abstract:** <http://bit.ly/2LIB1aB>

Cont.

Noted in Media Watch 24 June 2019 (#619, p.9):

- *JOURNAL OF URBAN HEALTH* | Online – 7 June 2019 – ‘**Utilization of advance care planning for homeless adults: Case studies.**’ The authors’ examined the feasibility and outcomes of advance care planning (ACP) in primary care for patients who have experienced homelessness. They found such efforts had significant impacts on patients’ hospital care and allowed their wishes to be honored when they lost capacity for medical decision-making, particularly at the end of life. The authors present six case studies demonstrating the outcomes of ACP in primary care for homeless adults and highlight lessons learned. **Abstract (w. list of references):** <http://bit.ly/2WOeaWe>

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).

Exploring the gender dimension of problems and needs of patients receiving specialist palliative care in a German palliative care unit: The perspectives of patients and healthcare professionals

BMC PALLIATIVE CARE | Online – 17 July 2019 – Gender disparities of specific symptoms and problems have frequently been observed in palliative care (PC) patients, but research rarely focused on the range of problems and needs affected by gender. The authors conducted semi-structured interviews with patients and healthcare professionals (HCPs) of a hospital-based PC unit to examine gender effects on patients’ problems and needs based on systematically gathered qualitative data. Seven categories of gender-specific problems and needs emerged: “physical symptoms, care and body image,” “psychological symptoms and emotional response,” “interaction with the PC team,” “use of professional supportive measures,” “activation of informal social networks,” “decision-making,” and “preservation of autonomy and identity.” Both patients and HCPs felt that female patients adopt more expressive coping strategies, have stronger need for communication with and support of HCPs, and activate an extended social network for support and decision-making. Further, both groups thought that male patients mainly rely on social support from partners, have higher expectations to be cared for at home, and have higher need for preservation of autonomy. **Full text:** <http://bit.ly/2O2fxS7>

Noted in Media Watch 23 July 2018 (#573):

- *CANADIAN JOURNAL OF NURSING RESEARCH* | Online – 19 July 2018 – ‘**Discourses reproducing gender inequities in hospice palliative home care.**’ This critical analysis sheds light on institutional discourses that reproduce gender inequities: discourses of difference and denial; discourses of individuality, autonomy, and choice; and, discourses of efficiency, objectivity, and rationality. Although gender was discounted, these neoliberal discourses reinforced traditional gender relations. Neoliberal discourses frame health and healthcare experiences as resulting primarily from individual behaviors and biomedical factors, permitting health-care providers and policy makers to overlook power relations and the socio-political forces that obscure gender inequities. **Abstract:** <http://bit.ly/2JMH1Wx>

Noted in Media Watch 18 May 2015 (#410, p.11):

- *CANCER* | Online – 14 May 2015 – ‘**Male-female patient differences in the association between end-of-life discussions and receipt of intensive care near death.**’ Patient gender plays a significant role in patient-physician communication, patients’ understanding of illness, and the aggressiveness of end-of-life (EoL) care. However, little is known about the extent to which gender differences in the effects of EoL discussions on EoL care contribute to gender differences in EoL care. This study was aimed at determining whether gender differences existed in the receipt of intensive care unit (ICU) care near death and in the association between EoL discussions and the receipt of EoL ICU care. Men with advanced cancers are more likely than women to receive aggressive, non-beneficial ICU care near death. **Full text:** <http://bit.ly/2NZmJ1t>

Dignity of the patient-family unit: Further understanding in hospice palliative care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 14 July 2019 – Findings of this study suggested that staff members viewed dignity as something that is reciprocally supported within the patient-family unit. Themes included respect, comfort, privacy, being informed and quality family time were common in the conceptualisation of dignity in patients and families; themes of being human and being self, autonomy and living with dignity were uniquely used to conceptualise patient dignity. Themes solely constituting family dignity included being included in care, being capable and being treated fairly. Cultural considerations, environmental factors, teamwork and patient/family-staff relationship were the factors identified by staff members that affected dignity in hospice palliative care. **Abstract:** <http://bit.ly/2JCC8kd>

Optimised clinical study recruitment in palliative care: Success strategies and lessons learned

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 July 2019 – Recruitment challenges to clinical research studies in palliative care (PC) settings, particularly in hospices, are well documented. However, a recent study – Hospice Inpatient Deep vein thrombosis Detection (HIDDEN) study – performed across five hospices in the U.K. recruited above target and on time. The authors describe strategies that aided successful recruitment in this study, and the lessons learnt for improving future studies. A recent review suggested that the ‘Social Marketing Mix Framework’ (SMMF) could help researchers with recruitment strategies in PC. The authors describe the recruiting strategies employed through the social marketing mix lens and consider if it would be a useful framework for future researchers to use at the planning stage. Successful recruitment strategies employed in HIDDEN study included: 1) Addressing particular study-related factors; 2) Ensuring all patients were screened and offered participation if eligible; 3) Reducing impact on the clinical team through dedicated research nurses at sites; 4) Addressing research team issues with cross-cover between sites, where geographically possible; and, 5) Regular video conferencing meetings for support and collaborative solving of challenges. Limited pre-existing research infrastructure at most of the recruiting hospices created particular challenges. The SMMF provides a potential structure to help researchers to plan recruitment. To fully streamline trial set up and in order for hospice involvement in research to be realised systematically, a centralised approach to governance, organisational culture change whereby hospices embrace research as a legitimate purpose and consistent access to research staff are identified as key strategic elements promoting recruitment to studies in hospices. **Abstract:** <http://bit.ly/2YRBqoi>



Noted in Media Watch 15 July 2019 (#622, p.11):

- *MORTALITY* | Online – 10 July 2019 – ‘**The performance of researching sensitive issues.**’ Comparatively little attention has been paid to the emotional labour and emotion work researchers perform and how it is shaped by the need to behave appropriately and in ways that are in keeping with the demands of the study setting. The authors draw on two research experiences, an ethnographic study into end-of-life care in care homes and an exploration into the role of the anatomical pathology technologist in a hospital mortuary to explore the tensions between conducting sensitive research and managing emotions. **Abstract:** <http://bit.ly/2Y6ydnS>

Noted in Media Watch 18 February 2019 (#602, p.8):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 12 February 2019 – ‘**Primary palliative care research: Opportunities and challenges.**’ This paper highlights the opportunities and challenges associated with primary palliative care research in the U.K., describing the methodological, ethical, logistical and gatekeeping challenges encountered in the ‘Community Care Pathways at the End of Life’ study and how these were addressed. Considerable difficulties were encountered with ethical permissions, with general practitioner, district nurse and bereaved carer recruitment and both quantitative and qualitative data collection. **Full text:** <http://bit.ly/2WVc3S1>



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

A review of the literature on family decision-making at end of life precipitating hospital admission

BRITISH JOURNAL OF NURSING | Online – 13 July 2019 – In collaboration with a local hospice, a literature review was undertaken to address the question: “What factors precipitate admission to hospital in the last few days of a person’s life for those who had expressed a preference to die at home?” Four electronic databases were searched, with a date range of 2008 to 2018. After 80 articles were screened, 13 were included in the review. The findings identified a number of barriers experienced by people with non-cancer conditions nearing the end of life (EoL) and their family carers, which inhibit the transition to EoL care. The findings suggest hospice support for non-cancer patients with a deteriorating health trajectory needs to precede patient and family recognition that EoL care is needed. **Abstract:** <http://bit.ly/2LkQmlz>

Treatability statements in serious illness: The gap between what is said and what is heard

CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2019;28(3):394-404. Empirical work has shown that patients and physicians have markedly divergent understandings of treatability statements (e.g., “This is a treatable condition,” “We have treatments for your loved one”) in the context of serious illness. Patients often understand treatability statements as conveying good news for prognosis and quality of life (QoL). In contrast, physicians often do not intend treatability statements to convey improvement in prognosis or QoL, but merely that a treatment is available. Similarly, patients often understand treatability statements as conveying encouragement to hope and pursue further treatment, though this may not be intended by physicians. This radical divergence in understandings may lead to severe miscommunication. The authors seek to better understand this divergence through linguistic theory... The divergence between the physician’s intended meaning and the patient’s received meaning can be understood to arise from the lack of shared experience between physicians and patients, and the differing assumptions that each party makes about conversations. **Abstract (w. list of references):** <http://bit.ly/32yCzU9>

Prognostication in palliative care

CLINICAL MEDICINE, 2019;19(4):306-310. An accurate prognosis about how long a terminally ill patient has left to live, when disclosed sensitively in open discussions, can facilitate patient-centred care and shared decision making. In addition, several guidelines, policies and funding streams rely, to some extent, on a clinician estimated prognosis. However, clinician predictions alone have been shown to be unreliable and over-optimistic. The factors underlying clinicians’ prognostic decisions (particularly at the very end of life) are beginning to be elucidated. As an alternative to clinicians’ subjective estimates, a number of prognostic algorithms and scores have been developed and validated, but only a few have consistently shown superiority to clinician predictions. Therefore, an element of uncertainty remains and this needs to be acknowledged when having conversations with patients and their families. Guidelines are available to advise clinicians about how to prepare for, participate in and record prognostic conversations. **Abstract:** <http://bit.ly/2XXAGwN>

Deprescribing in palliative care

CLINICAL MEDICINE, 2019;19(4):311-314. The use of multiple medications is common in palliative care, putting patients at risk of adverse events and a high tablet burden. Deprescribing is the process of reviewing and stopping potentially inappropriate medications in order to improve quality of life. Barriers to deprescribing exist meaning many patients will take multiple medications despite being in the final months of life. The OncPal deprescribing guideline is a useful tool to support the process for patients with a limited life expectancy. There is evidence for the safety of stopping certain medications, particularly those aimed at primary prevention. A systematic process of reviewing individual medications and their appropriateness is recommended. **Abstract:** <http://bit.ly/32GrX5E>

N.B. Additional articles on medications with questionable benefit at the end of life noted in 1 April 2019 issue of *Media Watch* (#608, pp.7-8).

Agreement with consensus statements on end-of-life care: A description of variability at the level of the provider, hospital, and country

CRITICAL CARE MEDICINE | Online – 11 July 2019 – The authors examined the contributions of provider, hospital, and country to variability in agreement with consensus statements about end-of-life care (EoLC). Data were drawn from a survey of providers' views on principles of EoLC obtained during the consensus process for the Worldwide End-of-Life Practice for Patients in ICUs Study.¹ Participants ... included physicians, nurses, and other providers: 1,068 providers from 178 hospitals and 31 countries. The authors examined views on cardiopulmonary resuscitation and withholding/withdrawing life-sustaining treatments. 1% strongly disagreed, 7% disagreed, 11% were neutral, 44% agreed, and 36% strongly agreed with declining to offer cardiopulmonary resuscitation when not indicated. Of the total variability in those responses, 98%, 0%, and 2% were explained by differences among providers, hospitals, and countries, respectively. After accounting for provider characteristics and hospital size, the variance partition was similar. Results were similar for withholding/withdrawing life-sustaining treatments. Variability in agreement with consensus statements about EoLC is related primarily to differences among providers.

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

1. 'Seeking worldwide professional consensus on the principles of end-of-life care for the critically ill. The Consensus for Worldwide End-of-Life Practice for Patients in Intensive Care Units (WELPICUS) Study,' *American Journal of Respiratory & Critical Care Medicine*, 2014;190(8). [Noted in 1 September 2014 issue of *Media Watch* (#373, p.8)] **Full Text:** <http://bit.ly/2XYMP8L>

Improving palliative and end-of-life care with machine learning and routine data: A rapid review

HEALTH RESEARCH BOARD: OPEN RESEARCH | Online – Accessed 15 July 2019 – In clinical practice, physician judgement is the core method of identifying end-of-life care (EoLC) needs, but has important limitations. Machine learning (ML) is a subset of artificial intelligence advancing capacity to identify patterns and make predictions using large datasets. ML approaches have the potential to improve clinical decision-making and policy design, but there has been no systematic assembly of current evidence. ML has the potential to support clinicians in improved decision-making by identifying those at heightened risk of inappropriate care, poor outcomes and mortality. To date studies have demonstrated capacity to improve mortality prediction. Other outcomes have not received equivalent attention. Applications of ML approaches to policy and practice remains formative. Derived results depend on available data and must be interpreted in this context. Future research must not only expand scope to consider other outcomes and longer timeframes, but also address individual needs and preferences in the context of prognosis, and engage with the profound ethical challenges of this emerging field.

Full text: <http://bit.ly/2LUETyU>



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Quality of life of older persons in nursing homes after the implementation of a knowledge-based palliative care intervention

INTERNATIONAL JOURNAL OF OLDER PEOPLE NURSING | Online – 12 July 2019 – The evaluation showed no increase in the quality of life (QoL) dimensions, which could be an expected result of a six-month educational palliative care (PC) intervention. The intervention group exhibited no decline in the QoL dimensions at follow-up. However, the control group showed significant declines in the sensory abilities, autonomy and social participation dimensions. It seems that the PC approach in the intervention in this study prevented unnecessary reductions in QoL by supporting sensory abilities, autonomy and social participation among frail older persons living in nursing homes. However, it is important to continue developing research-based knowledge about effective PC interventions as the proportion of frail older persons increases worldwide. **Abstract:** <http://bit.ly/2LWwmLE>

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- *PATIENT EDUCATION & COUNSELING* | Online – 27 June 2019 – ‘**Mechanisms by which end-of-life communication influences palliative-oriented care in nursing homes: A scoping review.**’ The authors summarize what is known about the potential mechanisms by which end-of-life communication may contribute to palliative-oriented care in nursing homes. Three mechanisms are identified: 1) Promotion of family carers’ understanding about their family member’s health condition, prognosis, and treatments available; 2) Fostering of shared decision-making between health care professionals and residents/family carers; and; 3) Using and improving knowledge about residents’ preferences. **Abstract:** <http://bit.ly/2Y3kRst>

Noted in Media Watch 3 June 2019 (#616, p.6):

- *BMC PALLIATIVE CARE* | Online – 31 May 2019 – ‘**Evaluation of person-centeredness in nursing homes after a palliative care intervention: Pre- and post-test experimental design.**’ Lessons learned from this study are to educate all staff at the participated nursing homes, more frequent training ... and specifically educate some staff at each nursing home to educate newly employed staff on the person-centred palliative care approach. Not only staff needs education, but also front leaders, since the study found lack of leadership and embedded organisational support for person-centred care. Further research could focus on investigating front leaders’ support to staff and removing obstacles for providing person-centred care. **Full text:** <http://bit.ly/2QzSAmW>

End-of-life decision making and treatment for patients with professional guardians

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 13 July 2019 – 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. The authors collected data about the guardianship appointment, the patient’s preferences, the guardian’s decision-making process and treatment outcomes of decedent patients represented by PGs who received care at Connecticut Veterans Affairs (VA) facilities from 2003 to 2013... There were 33 patients with PGs who died and had documentation of their EoL care. The guardian sought judicial review for 33%, and there were delays in decision making for 42%. In the last month of life, 29% of patients were admitted to the intensive care unit, intubated or underwent cardiopulmonary resuscitation; 45% received hospice care. Judicial review and high-intensity treatment were less common when information about the patient’s preferences was available. Rates of high-intensity treatment and hospice care were similar to older adults overall. Because high-intensity treatment was less likely when the guardian had information about a patient’s preferences, future work should focus on advance care planning for individuals without an appropriate surrogate. **Abstract:** <http://bit.ly/30yw6Xu>

Parents’ wishes for what they had or had not done and their coping after their infant’s or child’s neonatal intensive care unit/pediatric intensive care unit/emergency department death

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(4):333-343. This qualitative study asked 70 mothers and 26 fathers 3 open-ended questions... Mothers wished they spent more time with the child, chosen different treatments, advocated for care changes, and allowed the child his or her wishes. Fathers wished they had spent more time with the child and gotten care earlier. Mothers wished they had not agreed to child’s surgery/treatment, taken her own actions (self-blame), and left the hospital before the death. Fathers wished they had not been so hard on the child, agreed with doctors/treatment, and taken own actions (self-blame). Religious activities, caring for herself, and talking about/with the deceased child were the most frequent mothers’ coping strategies; those of the fathers were caring for self and religious activities. Both mothers and fathers wished they had spent more time with their child and had not agreed to surgery/treatments. The most frequent coping was caring for themselves, likely to care for the family and retain employment. Nurses must be sensitive to parents’ need for time with their infant/child before and after death and to receive information on child’s treatments at levels and in languages they understand. **Abstract:** <http://bit.ly/2GcuKK9>

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Related

- *NATIONAL CATHOLIC BIOETHICS QUARTERLY*, 2019;19(1):105-120. **'Medical futility in pediatric care.'** The transition from the paternalistic paradigm of the Hippocratic tradition to the present model of shared decision making has altered the patient-doctor relationship. This change has engendered conflicts between patients and physicians, especially in pediatric medicine, where the patients are dependent on their parents because of their inability to consent to an intervention independently. Navigating this complex relationship can become particularly fraught when medical futility is invoked. This situation is complicated further by the divergent approaches to shared decision making among physicians and the ethical perspectives these positions reflect. **First page view:** <http://bit.ly/2XWTXOF>

Meeting the needs of people who identify as lesbian, gay, bisexual, transgender, and queer in palliative care settings

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(4):286-290. The end-of-life (EoL) needs of people who identify as lesbian, gay, bisexual, transgender, and queer (LGBTQ) are in many ways identical to those of non-LGBTQ people; however, for a variety of reasons, they are at risk of receiving suboptimal care, irrespective of whether they are being cared for at home or in a nursing home, hospital, or hospice. Although research on the needs of LGBTQ people at the EoL is sparse, drawing on what is available this article explores some of their unique concerns that practitioners should consider during their interactions. **Abstract:** <http://bit.ly/2xNvvES>

Noted in Media Watch 27 May 2019 (#615, p.2):

- *KAISER HEALTH NEWS* | Online – 21 May 2019 – **'Inclusive care at the end of life: The LGBTQ+ experience.'** For a generation of lesbian, gay, bisexual, transgender and queer (LGBTQ+) people who lived through unprecedented social change, getting older poses new challenges. When it comes to seeking elder care, concerns about lack of services, discrimination, neglect and even abuse threaten to reverse recent progress. What are the hurdles to quality care that face growing numbers of aging LGBTQ+ people? <http://bit.ly/2HLann7>

N.B. Additional articles on EoL care for LGBTQ+ people noted in 10 December 2018 issue of Media Watch (#593, p.4 & p.14).

Improving attitudes and perceptions about end-of-life nursing on a hospital-based palliative care unit

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(4):272-279. Education intended to improve end-of-life (EoL) skills must address the affective/emotional component of nursing care. Evidence demonstrates that emotional engagement and resilience among healthcare providers are correlated with improved quality outcomes and, conversely, that burnout and stress negatively affect patient safety. Addressing the emotional needs of healthcare providers is critical to improving quality throughout the health-care system. An evidence-based workshop was implemented among direct care staff on a hospital-based palliative care unit, with the goal of fostering emotional engagement to improve staff perceptions and attitudes about caring for patients at or near the EoL. Although perceptions about quality of death were not affected by this intervention, there was a significant improvement in attitudes about EoL nursing care. Qualitative feedback also reflected appreciation for small group discussions and opportunities to debrief with peers away from the unit. This intervention reflected the value of emotional engagement in educational efforts to improve EoL nursing care. **Abstract:** <http://bit.ly/2Jz2NhR>



Media Watch Online

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Models of pediatric palliative oncology outpatient care-benefits, challenges, and opportunities

JOURNAL OF ONCOLOGY PRACTICE | Online – 19 July 2019 – Although the bulk of current pediatric palliative care (PPC) services are concentrated in inpatient settings, the vast majority of clinical care, symptom assessment and management, decision-making, and advance care planning occurs in the outpatient and home settings. As integrated PPC/pediatric oncology becomes the standard of care, novel pediatric palliative oncology (PPO) outpatient models are emerging. The optimal PPO model is unknown and likely varies on the basis of institutional culture, resources, space, and personnel. The authors reviewed five institutions' unique outpatient PPO clinical models with their respective benefits and challenges. This review offers pragmatic guidance regarding PPO clinic development, implementation, and resource allocation. Organizations that have overcome personnel, funding, and logistical challenges can serve as role models for centers developing PPO clinic models. In the absence of a one-size-fits-all model, pediatric oncology and PPC groups can select, tailor, and implement the model that best suits their respective personnel, needs, and capacities. **Abstract:** <http://bit.ly/2y0n0GK>

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- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 19 July 2019 – ‘**Children’s unmet palliative care needs: A scoping review of parents’ perspectives.**’ Children with life-limiting conditions often have complex needs, making it challenging for services to provide satisfactory care. Few studies consider whether services actually meet families’ needs by exploring and identifying the parents’ perspectives of unmet needs. Fifty-five papers met the authors’ scoping review criteria. The findings suggest many unmet needs from the parent’s perspective, across several aspects of the Quality Standards & Children’s Palliative Care Frameworks. Further research is needed which explores the parent’s unmet needs in palliative care services. **Abstract:** <http://bit.ly/2O7CtQ6>

Palliative care in trauma: Not just for the dying

JOURNAL OF TRAUMA & ACUTE CARE SURGERY | Online – 8 July 2019 – Palliative care (PC) is indicated in patients with functional dependency and advanced care needs in addition to those with life-threatening conditions. Older trauma patients have PC needs due to increased risk of mortality and poor long-term outcomes. The authors hypothesized that older trauma patients discharged alive with poor outcomes are not easily identified nor receive PC interventions. 315 (54%) of 585 patients analyzed had poor outcomes. PC utilization was very high for older trauma patients who died in hospital. In contrast, the majority of those who were discharged alive, but with poor outcomes, did not have PC. Development of triggers to identify older trauma patients who would benefit from PC, could close this gap and improve quality of care and outcomes. **Abstract:** <http://bit.ly/32qPMY1>

Multi-disciplinary palliative care is effective in people with symptomatic heart failure: A systematic review and narrative synthesis

PALLIATIVE MEDICINE | Online – 15 July 2019 – Overall, the results of this review support the use of multi-disciplinary palliative care in people with advanced heart failure, but trials do not identify who would benefit most from specialist palliative referral. There are no sufficiently robust multi-centre evaluation phase trials to provide generalisable findings. Use of common population, intervention and outcomes in future research would allow meta-analysis. **Abstract:** <http://bit.ly/2Gdic5i>

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- *CANADIAN FAMILY PHYSICIAN*, 2019;65(7):479. ‘**End-of-life discussions in advanced heart failure.**’ Guidelines recommend discussing goals of care (GoC) and end-of-life (EoL) issues with patients with advanced heart failure; and, as specialists do not consistently do this, primary care providers are often left with this critical role. Using criteria for advanced HF, mortality can be as high as 75% at 1 year. There is a clear need for advance care planning and GoC and EoL discussions, as well as a palliative care approach. **Full text:** <http://bit.ly/2LmohjR>

N.B. Additional articles on palliative care for patients living with heart failure noted in 27 May 2019 issue of *Media Watch* (#615, pp.9-10).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *INTERNATIONAL JOURNAL OF LAW & PSYCHIATRY*, 2019;66. ‘**Euthanasia requests in a Canadian psychiatric outpatient clinic...**’ The Canadian province of Quebec enacted in 2014 a legislation that permitted medical assistance in dying (MAiD) under specific conditions and the rest of Canada followed suit in June 2016. In this article, the authors present the cases of two patients who made a request for MAiD to their treating psychiatrist in an outpatient clinic. While one is advanced in age and suffering from intense physical and psychic pain with little if any psychiatric co-morbidity, the other is a young and medically healthy woman who nonetheless suffers from extensive psychiatric co-morbidity. This article discusses both cases in light of recent scientific literature and case law that is slowly emerging in Canada, focusing on the concepts of the end of life and its legal definition as well as psychic suffering and its management in those wishing to receive physician-assisted dying. The authors stress the need to clarify the definition of treatment resistance, the necessity to determine each physician’s role when many are involved, as well as the importance of treating psychic pain holistically, which can sometimes require going beyond standard psychiatric care. **Abstract:** <http://bit.ly/2YVYoKW>
- *INTERNATIONAL JOURNAL OF PUBLIC HEALTH* | Online – 11 July 2019 – ‘**Commonalities and differences in legal euthanasia and physician-assisted suicide in three countries: A population-level comparison.**’ The authors describe and compare euthanasia and physician-assisted suicide (EAS) practice in Flanders, Belgium (BE), The Netherlands (NL) and Switzerland (CH). They studied 349 EAS deaths in BE (4.6% of all deaths), 851 in NL (4.6% of all deaths) and 65 in CH (1.4% of all deaths). People who died by EAS were mostly aged 65 or older (BE: 81%, NL: 77% and CH: 71%) and were mostly diagnosed with cancer (BE: 57% and NL: 66%). Home was the most common place of death in NL (79%), while in BE and CH, more variation was found regarding to place of death. The decision to perform EAS was more frequently discussed with a colleague physician in BE (93%) and NL (90%) than in CH (60%). EAS practice characteristics vary considerably in the studied countries with legal EAS. In addition to the legal context, cultural factors as well as the manner in which legislation is implemented play a role in how EAS legislation translates into practice. **Abstract:** <http://bit.ly/2JAojCB>
- *JOURNAL OF HEALTH SERVICES RESEARCH & POLICY*, 2019;24(3):207-216. ‘**Medical assistance in dying: Implications for health systems from a scoping review of the literature.**’ While legal in several countries, the implementation of medical assistance in dying (MAiD) is met with ethical, legislative and clinical challenges, which are often overshadowed by moral discourse. The authors’ aim was to conduct a scoping review to explore key barriers for the integration of MAiD into existing health systems. The final review included 35 articles. Six categories of implementation challenges emerged: regulatory, legal, social, logistical, financial and compatibility with palliative care. Within four of the six identified implementation barriers (regulatory, legal, social and logistical) were sub-themes, which described barriers related to legalizing MAiD in more detail. Despite multiple challenges related to its implementation, MAiD remains a requested end-of-life option, requiring careful examination to ensure adequate integration into existing health services. Comprehensive models of care incorporating multidisciplinary teams and regulatory oversight alongside improved clinician education may be effective to streamline MAiD services. **Abstract:** <http://bit.ly/2GgPn7W>

Publishing Matters

Fixing healthcare’s replication crisis is important for researchers and patients

STAT | Online – 16 July 2019 – We are awash in articles reporting new study results. Whether it’s a potential cure for an illness, daunting statistics about healthcare outcomes, or the latest take on what makes a healthy diet, we’re receiving more information than we’ve ever had before nudging us toward making decisions about our health. But are we getting accurate information? Dr. John Ioannidis, a statistician and professor of medicine at Stanford, recently joined three dozen health researchers in a Stanford lecture hall to explain why most research findings are false. Of the most widely cited health research studies of the last decade, he found



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that only a minority could be replicated, and at least 1 in 6 had actually been contradicted by later studies. Few of the cases loannidis cited were about outright fraud. Instead, most research claiming to have an effect among specific groups of people had used poor statistical methods that failed to support their conclusions. More often than not, researchers had simply sliced and diced their data until the results seemed significant rather than null. But still, loannidis pointed out that most claims in the health research field today are simply wrong. This mismatch is leading to the “replication crisis” – an alarming trend of studies that can’t be duplicated by other parties. While it isn’t limited to health research, that’s where it potentially poses the biggest problem. **Full text:** <http://bit.ly/2xOQG9H>

Media Watch: Editorial Practice

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