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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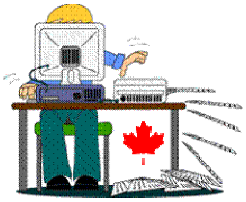


Compiled & Annotated by Barry R. Ashpole

Evidence-based palliative and end-of-life care: Scroll down to Specialist Publications and 'Barriers and facilitators to knowledge transfer and exchange in palliative care research' (p.7), in *BMJ Evidence Based Medicine*.

Canada

It took two years to close a cruel loophole in palliative care, even with legislative consensus. Why?

ONTARIO | CBC News (Toronto) – 29 June 2018 – In 2016, 48-year-old Dan Duma was working in Alberta when he received the devastating news that he had terminal liver cancer. Duma was originally from Ontario, so he went home to be with his family. Home was where he wanted to die, a goal normally supported by publicly funded medical equipment, nurses and other care providers. Tragically, Duma didn't qualify to access palliative care at home or in a hospice because of a mandatory three-month waiting period for those who move to Ontario from another province. The only option for Duma was to suffer without home care until he could bear it no more and then go to the hospital to die. Ultimately, Duma's PC physician, Dr. Darren Cargill, managed to pull strings and secure emergency funding to support Duma's choices in his final weeks of life. One month into his three-month wait, Duma died in a hospice just outside his hometown of Windsor. This case highlighted a glaring loophole in provincial health care, whereby patients have no access to out-of-hospital and non-physician services for several months when they move provinces. In short, hospital care is exempt from the three-month-waiting period because of the way the Canada Health Act enshrines certain services as essential. But this is a relic of Canadian medicine of the past, where for decades there was little else in the way of public health care except for doctors and hospitals. https://goo.gl/wpeb1A

Extract from CBC News report

Nowadays, home and hospice service are fundamental parts of our system and absolutely critical to delivering high quality palliative care. Yet much of the problem with closing these loopholes is that there is no clear mechanism in place for health care providers to push for progress within our current system. The Ministry of Health is many steps removed from the realities of front line care, and providers are often stuck fighting against nonsensical rules or looking for backdoor ways to alleviate the suffering caused by thoughtless red tape.

Specialist Publications

'Using simulation modelling to test the impact of future demand for end-of-life care' (p.9), in *Healthcare Management Forum.*

Cont.

Noted in Media Watch 21 November 2016 (#488, p.1):

- ONTARIO | *The Windsor Star* – 17 November 2016 – **'Queen's Park votes favourably on end-of-life Dan's Law.'** Bill 54, to amend the Home Care & Community Services Amendment Act (1994), has passed second reading by the provincial parliament. Home care is currently not subject to Canada's inter-provincial billing agreement. https://goo.gl/NVLUTR

Ontario judge refuses family's plea to keep brain dead woman on life-support

ONTARIO | CBC News (Toronto) – 26 June 2018 – An Ontario court has rejected a Toronto-area family's plea to keep their 27-year-old daughter, who has been declared brain dead, on life-support. Taquisha McKitty's parents were seeking an order to keep her on a mechanical ventilator, arguing she continues to show signs of life and that her Christian fundamentalist beliefs say she's alive as long as her heart's still beating. However, the Ontario Superior Court of Justice ruled, in a complex and potentially precedent-setting decision, that McKitty can be considered dead and can be removed from life-support. However, judge Lucille Shaw's decision notes doctors have found "uncontroverted medical evidence" that there's no blood flow to McKitty's brain and that it will not be able to recover. The movements, the decision notes, originate in the spinal cord and "do not involve any brain activity." That has been proven by a series of medical tests, Shaw wrote. Unlike four other Canadian provinces, including Manitoba and Nova Scotia, Ontario does not have a statutory definition of death, the court decision notes. Instead, death in Canada is determined by physicians in accordance with accepted medical practice. "There is no legislation that requires physicians to consider an individual's views, wishes or religious beliefs as factors to be considered in the determination of death," the judge wrote in her decision. https://goo.gl/xvVmjk

Noted in Media Watch 20 November 2017 (#539, p.1):

- ONTARIO | CBC News (Toronto) – 16 November 2017 – **'Science must be the guiding factor when diagnosing brain death.'** Ontario courts have ordered artificial breathing machines remain attached to Taquisha McKitty and Shalom Ouanounou after their families launched legal challenges in order to prolong treatment. Both families have claimed that their loved ones are not dead by their respective religions' definitions of death. Teams of doctors in each case, however, have established irreversible death of the brain, which means that medically speaking, McKitty and Ouanounou are gone. The courts are nevertheless being asked to reaffirm decades of science, medicine and ethics, while also weighing the value of religious belief. https://goo.gl/9TACZ9

N.B. Additional articles on defining death noted in this issue of Media Watch.

More than one-quarter of Nova Scotians learn of lung cancer diagnosis in ER...

NOVA SCOTIA | Global TV News (Halifax) – 25 June 2018 – One Halifax radiologist is sounding the alarm on the need for an organized early-detection program for lung cancer after a review she led revealed results that are shocking seasoned medical professionals. Dr. Manos says the review shows more than one-quarter of Nova Scotians find out they have lung cancer in emergency departments and often the disease has already progressed to a stage that's too advanced to cure. According to Manos, this isn't the first time a proposal to bring in an early-detection program has been pitched to the Nova Scotia Health Authority (NSHA). She says in 2016, the Canadian Task Force [on Preventive Health Care] issued recommendations for provinces to implement lung-cancer screening for high-risk patients.[1] Following those recommendations, Manos says a proposal was submitted to NSHA in 2015, but financial barriers appear to be stalling the process. "Unfortunately, when you diagnose lung cancer at a late stage, three or four, the expense is quite high. So even if somebody can't have surgery, there are expenses for every effort we can make to treat them with chemotherapy and with other medications. There's also the expenses related to the palliative care these patients need," she added. The NSHA says its monitoring the results of two-pilot programs currently underway in Alberta and Ontario to determine whether a similar program would work for Nova Scotia. https://goo.gl/t8g24N

1. 'Lung Cancer: Summary of recommendations for clinicians and policy-makers,' Canadian Task Force of Preventive Health Care, 2016. **Download/view at:** https://goo.gl/joCgJX

U.S.A.

Study debunks notion that large chunks of Medicare go to lost causes

SCIENCE DAILY | Online – 28 June 2018 – After examining millions of medical records, a new study found that although Medicare spending is concentrated among people who die, there is very little Medicare spending on patients whose death within the year is highly likely.[1] For example, the researchers discovered, less than 5% of Medicare spending is applied to the single highest-risk percentile of all individuals – and their predicted one-year mortality rate is still just 46%. The study also illuminates the general circumstances of late-in-life mortality. Fewer than 10% of people who die in a given year have a predicted one-year mortality rate over 50%. As the researchers found, even when people are admitted to a hospital in what turns out to be their last year of life, fewer than 4% of those patients have a predicted one-year mortality rate of 80% or higher at the time of admission. In a sense, the study shows, the apparent concentration of spending on last-year-in-life patients is a by-product of the fact that even relatively low-mortality health scenarios for the elderly will include a certain number of deaths – not that the individual treatment decisions represent long shot cases. https://goo.gl/TrNmS6

Specialist Publications

'"Meet me where I am": Removing barriers to end-of-life care for homeless veterans and veterans without stable housing' (p.5), in *American Journal of Hospice & Palliative Medicine*.

'Defining provider-prioritized domains of quality in pediatric home-based hospice and palliative care: A study of the Ohio Pediatric Palliative Care & End-of-Life Network' (p.8), in *Journal of Palliative Medicine*.

1. 'Predictive modeling of U.S. health care spending in late life,' *Science*, 2018;360(6296):1462-1465. **Abstract:** https://goo.gl/LioPPT

Related

- CALIFORNIA | *The Sacramento Bee* – 25 June 2018 – **'This type of care can sharply reduce medical costs, so why aren't doctors ordering it?'** Doctors can improve the quality of life for their seriously ill patients while also reducing the patients' medical expenses if they make use of one particular care model, so why aren't they using it? The biggest hurdle might well be the words used to describe it, said Dr. Jeanine Ellinwood, who leads a team in the specialized field. People hear them, she said, and think immediately of hospice care. It's not. It's palliative care, she said, and yes, there is a difference. https://goo.gl/PjMcVA

Compassionate release for dying prisoners underused: Report

WASHINGTON DC | Families Against Mandatory Minimums – 27 June 2018 – The non-profit advocacy group has released a comprehensive, state-by-state report on the early-release programs available to prisoners struggling with certain extraordinary circumstances, such as a terminal or age-related illness. The report takes a deep dive into the regulations and requirements of these programs in each state, including the varying categories of release, eligibility criteria, and reporting. The analysis also reveals a troubling number of barriers faced by prisoners and their families when applying for early release. The report is accompanied by a comparison chart, 21 recommendations for policymakers, and 51 individual state memos. **Download/view report at:** https://goo.gl/vsngvp

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 May 2018) can be downloaded/viewed at: https://goo.gl/YLckx6

Fewer people are dying in hospitals

OREGON | Oregon Public Broadcasting – 25 June 2018 – Fewer people are dying in hospitals, according to a new study by Oregon Health & Science University (OHSU) and Brown University.[1] Lead researcher Joan Teno says people generally prefer to die at home or in an assisted living facility, surrounded by family – rather than attached to a machine in an intensive care unit. And she found that in-hospital deaths decreased from 33% in 2000 to about 20% in 2015. In addition, the number of patients being moved to different health care facilities during the last three days of life decreased from 14% in 2009 to less than 11% in 2015. "This tells me we're on the right path," said Teno, who is a senior scholar at the OHSU Center for Ethics in Health. "We're listening to people who tell us they don't want to die in a hospital setting as we're expanding access to hospice and palliative care teams." Teno said it's not easy to tease out the reasons why fewer people are dying in hospitals, but she thinks penalties introduced in the Affordable Care Act are playing a role. https://goo.gl/bD6ZcR

1. 'Site of death, place of care, and health care transitions among U.S. Medicare beneficiaries, 2000-2015,' *Journal of the American Medical Association*, published online 25 June 2018 **Full text:** https://goo.gl/1Pa4Zv

International

Results of the largest ever multi-morbidity trial in primary care challenge current thinking

U.K. (England & Scotland) | University of Bristol (Centre for Academic Primary Care) – 28 June 2018 – In the largest ever trial of an intervention to treat people with multiple long-term conditions (multi-morbidity) in primary care, researchers at the Universities of Bristol, Manchester, Dundee and Glasgow found that the patient-centred approach taken improved patients' experience of their care but did not improve their health-related quality of life.[1] This is a challenge to current thinking on which U.K. and international guidelines are based. One in four people in the U.K. and the U.S. have two or more long-term health conditions, increasing to two-thirds for patients aged over 65, placing a major strain on health services. Conditions include diabetes, heart disease and asthma, and can include mental health conditions such as depression and dementia. Multi-morbidity is associated with reduced quality of life, worse physical and mental health, and increased mortality. Treatment for multi-morbidity places an additional burden on patients, who may have to take large numbers of drugs, make lifestyle changes and attend numerous appointments for health care. The study tested a new approach to caring for people with three or more long-term conditions, which aimed to improve their health-related quality of life and experience of patient-centred care, and reduce their burden of illness and treatment compared with usual care. https://goo.gl/b9XbL1

1. 'Management of multi-morbidity using a patient-centred care model: A pragmatic cluster-randomised trial of the 3D approach,' *The Lancet*, published online 28 June 2018. **Full text:** https://goo.gl/4EeD4S

Specialist Publications

'Adequate, questionable, and inadequate drug prescribing for older adults at the end of life: A European expert consensus' (p.8), in *European Journal of Clinical Pharmacology*.

'End-of-life care in Scotland: Trends in the population in need of palliative care' (p.9), in *International Journal of Population Data Science.*

'Re-framing global palliative care advocacy for the sustainable development goal era: A qualitative study of the views of international palliative care experts' (p.10), in *Journal of Pain & Symptom Management*.

'New European Academy of Neurology guideline on palliative care in multiple sclerosis' (p.12), in *Medscape*.

'"Old age is cruel": The right to die as an ethics for living' (p.12), in *The Australian Journal of Anthropology*.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | Associated Press (London) – 27 June 2018 – **'U.K. court rules against dying man's bid for assisted suicide.'** Britain's Court of Appeal has rejected an attempt from a terminally ill man to overturn the country's blanket ban on assisted suicide, ruling that such a decision needs to be made by politicians in Parliament. Judges expressed their "deep sympathy" with Noel Conway, a 68-year-old man with motor neuron disease who is wheelchair-bound and requires nearly constant help to breathe. Conway argued that British law's outlawing of assisted suicide infringed upon the European Convention on Human Rights. The ruling judges said it was "virtually unanimous" that Parliament was a better forum for deciding whether to legalize assisted suicide than the courts. Conway has previously said he doesn't plan to die immediately, but wants the option of an assisted death in his final months. https://goo.gl/14YCgd

Specialist Publications

"Meet me where I am": Removing barriers to end-of-life care for homeless veterans and veterans without stable housing

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 June 2018 – The core emergent theme [in this study] in the words of veterans and health-care workers was "meet me where I am," a statement of what many veterans want most from their health care. Barriers and facilitators often reflected the presence or absence of important factors such as relationship and trust building, care coordination and flexibility, key individuals and services, and assistance in navigating change. These findings suggest that to improve health care for veterans without stable housing (VWSH), interventions must be multifaceted, including a suite of support services, flexibility and creative problem-solving, and adaptations in communication approaches. The authors offer specific recommendations for improving end-of-life care for VWSH based on these findings. **Abstract:** https://goo.gl/rh59Tq

N.B. Selected articles on palliative and end-of-life (EoL) care for the homeless noted in the 18 June 2018 issue of Media Watch (#568, p.11). Additional articles on palliative and EoL care specifically for the homeless in the U.S. noted in the 28 May 2018 issue of Media Watch (#565, p.12).

Towards a public health approach for palliative care: An action-research study focused on engaging a local community and educating teenagers

BMC PALLIATIVE CARE | Online – 29 June 2018 – Although attention to palliative care (PC) is increasing, further developments and policy initiatives are needed to improve access to and quality of PC for all citizens who are in need of this type of care. The following policy implications can be drawn based on the findings of this study in a community parish in Portugal. First, while the study highlights the positive impact of education initiatives about PC in early ages, further research is needed to assess the actual impact of education about PC in the acquisition of specific knowledge, development of competences and change of attitudes among teenagers and younger age groups (e.g., children). Second, education about palliative and end-of-life care should be promoted at local communities, for instance in primary and secondary schools, to foster community involvement, participation and empowerment. Finally, compassionate communities, described as networks that could encourage people to take some active responsibility for care and recognize that ageing and dying, death and bereavement are part of everyday life and happen to everyone, could and should be promoted to enhance the health and wellbeing of all citizens at the end of their life. **Full text:** https://goo.gl/gsN7x2

N.B. Additional articles on initiatives to educate young people about palliative and end-of-life care noted in the 4 June 2018 issue of Media Watch (#566, p.7).

End-of-life care in Canada

The interaction of socioeconomic status with place of death: A qualitative analysis of physician experiences

BMC PALLIATIVE CARE | Online – 20 June 2018 – This study provides preliminary insights into the key factors that influence home death, and defines the mechanisms by which they and socioeconomic status interact. These findings were informed by the perceptions of home palliative care physicians in an urban setting in Toronto, Canada. Study participants noted three categories of factors that affect a successful home death: 1) Patient characteristics. 2) Physical environment: and, 3) Support networks. While socioeconomic status was not seen by physicians as the primary determinant of a patient's ability to die a home, a higher socioeconomic status was perceived to interact with these three categories of factors by strengthening support networks, optimizing physical home environments, and increasing patient comfort with home death. Possible areas of intervention to increase access to home death focused on better support for patients and families through increased resources and advocacy. Increasing the agency of those who prefer home death in an equitable way is a public policy imperative and should be prioritized by clinicians and policy-makers. **Full text:** https://goo.gl/2sv2Qn

Related

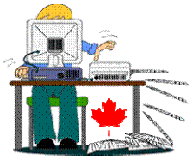
- *ACTA ONCOLOGICA* | Online – 27 June 2018 – **'Access to supportive care during and after cancer treatment and the impact of socioeconomic factors.'** Socioeconomic and demographic factors impact access to supportive care services. The cancer care providers seem to prioritize access to supportive care to patients that have complex care needs, such as patients undergoing multimodality cancer treatment. However, more effort is required to increase access and individualize the supportive care resources. Information regarding patient advocacy groups and second medical opinions particularly need to be improved as does the number of patients being offered a refereed to palliative care. **Full text:** https://goo.gl/6qaTVV

Noted in Media Watch 18 June 2018 (#568, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 June 2018 – **'Race/ethnicity, socioeconomic status, and healthcare intensity at the end of life.'** The authors identified 22,068 decedents with chronic illness cared for at a single healthcare system in Washington State who died between 2010 and 2015 and linked electronic health records to death certificate data. Socioeconomic disadvantage accounted for some of the higher intensity in racial/ethnic minorities, but most of the effects were direct effects of race/ethnicity. **Abstract:** https://goo.gl/MQsakF

Noted in Media Watch 24 July 2017 (#522, p.12):

- *INTERNATIONAL JOURNAL OF ENVIRONMENTAL & PUBLIC HEALTH RESEARCH* | Online – 18 July 2017 – **'Socioeconomic differences in and predictors of home-based palliative care health service use in Ontario, Canada.'** This study demonstrates that both the propensity and intensity of home-based nurse and personal support worker visits fell with socioeconomic status. These findings may assist health service planners in the appropriate allocation of resources and service packages to meet the complex needs of palliative care populations. **Full text:** https://goo.gl/Uv6gFH



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://goo.gl/5CHoAG

Barriers and facilitators to knowledge transfer and exchange in palliative care research

BMJ EVIDENCE BASED MEDICINE | Online – 25 June 2018 – Limited evidence exists as to how palliative care (PC) researchers use existing models to support their practice and to what extent they are perceived as effective. Ten themes were identified [in this study] and categorised as either barriers or facilitators to knowledge transfer and exchange (KTE). Perceived barriers included inadequate time and funding, limited institutional capacity, competing priorities, weak communication channels and negative perceptions of PC. Perceived facilitators included dedicated time and resources, aligned priorities, strong professional networks, multipronged approach and KTE experience. In order to improve the quality, acceptability and reach of palliative research, it is vital that researchers improve their understanding of KTE within the context of PC, moving beyond academic dissemination to achieve research-informed practice by overcoming barriers to KTE through facilitated action. This study provides an overview of factors that influence KTE planning and implementation among PC researchers. **Abstract:** https://goo.gl/hvPDor

N.B. Additional articles on palliative care research noted in the 19 February 2018 issue of Media Watch (#551, pp.11-12).

Related

- *REVISTA DA ESCOLA DE ENFERMAGEM DA UNIVERSIDADE DE SÃO PAULO* | Online – 25 June 2018 – **'The scenario of scientific publication on palliative care in oncology over the last 5 years: A scoping review.'** A significant number of articles related to palliative care (PC) in oncology, which mainly address topics such as professional and team practices, diagnoses and prognoses, and quality of life. The profile drawn by the results, as well as the recommendation grades and the lowly expressive levels of evidence found in the studies, reflect the practice of PC, which is still largely empirically performed and without theoretical-scientific foundation. **Abstract:** https://goo.gl/XGkY7h

N.B. Click on respective icons to access full text in either English or Portuguese.

Supporting parent caregivers of children with life-limiting illness

CHILDREN | Online – 26 June 2018 – Optimal pediatric palliative care (PPC) includes care for both the child and the family. The well-being of children depends in large part on their parents' well-being. The presence and involvement of parents in every aspect of their child's care is essential to good care. The role of parents as primary caregivers to the ill child means that parents and practitioners are partners in decisions of care, and that information about the ill child should be provided for the parents and for the ill child. Therefore, care for parents can reduce the distress of both the parental caregiver and the child with life-limiting illness. Even if it is in referral, PPC should meet the needs of its expanding complex chronic illness population by more broadly assessing for/meeting family needs. Parents are a critical component of a child's well-being and the PPC interdisciplinary team should strive to provide routine psychosocial assessment, evidence-based interventions, shared decision-making, organized respite, and attention to distress for all parental caregivers. In so doing, PPC meets its goals of caring for the child in their primary context – in their family. **Full text:** https://goo.gl/13R8eJ

The last 2 years of life for children with severe physical disability: Observations from a tertiary paediatric centre

JOURNAL OF PAEDIATRICS & CHILD HEALTH | Online – 26 June 2018 – The authors investigated whether there is a difference between children with progressive and non-progressive aetiologies of severe physical disability (SPD). The majority of children [i.e., the patient population studied] were admitted in the 6 months before their death and over a third were admitted to the intensive care unit. There was a significant increase in the frequency of hospital admissions as the study cohort approached death. The majority of children with SPD were offered a referral to a PC service, with referrals more likely in children with progressive SPD (90%) compared to children with non-progressive SPD (57%). While approximately 60% of children in each cohort had an advance care plan, there was a trend towards this being formalized earlier in children with PSPD. The increase in hospital admissions prior to death in children with SPD suggests an opportunity for greater consistency in offering ACP and PC, especially to those with NPSPD. **Abstract:** https://goo.gl/EZ2XkZ

Cont.

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 June 2018 – **'Defining provider-prioritized domains of quality in pediatric home-based hospice and palliative care: A study of the Ohio Pediatric Palliative Care & End-of-Life Network.'** In 2017, the Ohio Pediatric Palliative Care & End-of-Life Network (OPPEN) published nine domains of high-quality care for pediatric home-based hospice and palliative care (HBHPC). Eight domains established by the National Consensus Project (NCP) were validated for pediatric HBHPC, and a ninth domain of "continuity and coordination of care" was added. Definition criteria were established for the nine domains of quality in HBHPC previously identified. In the course of analysis, bereavement care was established as a 10th domain of quality, and definition criteria generated. This is the first study to define domains of quality for pediatric HBHPC, and the second to leverage the infrastructure of a pediatric HPC state-wide consortium toward this work**. Abstract:** https://goo.gl/M8674x

Adequate, questionable, and inadequate drug prescribing for older adults at the end of life: A European expert consensus

EUROPEAN JOURNAL OF CLINICAL PHARMACOLOGY | Online – 23 June 2018 – In this study, 40 European experts in geriatrics, palliative medicine, general practice, pharmacy, and clinical pharmacology from 10 different countries provided their professional opinion drug prescribing in older adults aged 75 years or older with an estimated life expectancy of ≤ 3 months. Panelists were given the opportunity to differentiate between the continuation and the initiation of drug therapy. Based on these results, the authors developed a consensus list of adequate, questionable, and inadequate drugs for older adults near the end of life (EoL). The expert panel reached consensus on a set of 14 drug classes deemed as "often adequate," 28 drug classes deemed "questionable," and 10 drug classes deemed "often inadequate" for continuation during the last 3 months of life. Regarding the initiation of new drug treatments, the panel reached consensus on a set of 10 drug classes deemed "often adequate," 23 drug classes deemed "questionable," and 23 drug classes deemed "often inadequate." Consensus remained unachieved for some very commonly prescribed drug treatments (e.g., proton-pump inhibitors, furosemide, haloperidol, olanzapine, zopiclone, and selective serotonin reuptake inhibitors). In the absence of high-quality evidence from randomized clinical trials, these consensus-based criteria provide guidance to rationalize drug prescribing for older adults near the EoL. **Full text:** https://goo.gl/wtWTJ7

Noted in Media Watch 30 April 2018 (#561, p.6):

- *AGE & AGEING* | Online – 23 April 2018 – **'Drug consumption and futile medication prescribing in the last year of life: An observational study.'** Hospital physicians have an opportunity to prioritize essential medications and de-prescribe potentially futile medications. The mean age of participants in this study was 80.8; 49.3% were female, and 63.7% were severely frail. The median number of days spent in hospital in the last year of life was 32. During all hospitalizations, the mean number of individual medications consumed was 23.8. One-in-six patients consumed 35 or more medications in their last year. **Abstract:** https://goo.gl/s6Fpbv

Which patients with heart failure should receive specialist palliative care?

EUROPEAN JOURNAL OF HEART FAILURE | Online – 28 June 2-18 – The authors investigated which patients with heart failure (HF) should receive specialist palliative care (SPC) by first creating a definition of need for SPC in patients hospitalised with HF using patient-reported outcome measures (PROMs) and then testing this definition using the outcome of days alive and out of hospital (DAOH). They also evaluated which baseline variables predicted need for SPC and whether those with this need received SPC. SPC need was defined as persistently severe impairment of any PROM without improvement (or severe impairment immediately preceding death). The authors then tested whether need for SPC, so defined, was reflected in DAOH, a measure which combines length of stay, days of hospital re-admission, and days lost due to death. Of 272 patients recruited [for this study], 74 (27%) met the definition of SPC needs. These patients lived one third fewer DAOH than those without SPC need (and less than a quarter of quality of life-adjusted DAOH). Twenty-four per cent of patients with SPC needs actually received SPC. **Abstract:** https://goo.gl/zn1WrH

Using simulation modelling to test the impact of future demand for end-of-life care

HEALTHCARE MANAGEMENT FORUM | Online – 28 June 2018 – Health systems globally are exploring new models of care to address the increasing demand for palliative, hospice and end-of-life care (EoLC). Yet few tools exist, however, at the population level to explore "what if" scenarios and test, in a "cost avoidance environment," the impact of these new care models on policy, workforce, technology, and funding. This article introduces the application of scenario-based "what if" thinking and discrete event simulation in strategic planning for a not-for-profit hospice organization. The authors describe how a set of conceptual models was designed to frame discussions between strategic partners about the implications and alternatives in implementing a new, integrated service model for palliative and EoLC. **Abstract:** https://goo.gl/E4eqxz

End-of-life care in Scotland: Trends in the population in need of palliative care

INTERNATIONAL JOURNAL OF POPULATION DATA SCIENCE | Online – 11 June 2018 – Estimation of population-wide palliative care (PC) needs is crucial for end-of-life care planning, and literature around it has grown in the last years. However, no estimates have yet been published for Scotland. This paper provides estimates of how many people require PC in Scotland and describes changes in the composition of this sub-population. What are their living arrangements? How have their medical conditions, health service use, and health trajectories changed? While a recent paper suggests that PC need in England & Wales has increased from 72.5% in 2006 to 74.9% in 2014,[1] the share of people with a PC need among all deaths in Scotland has decreased from 80.6% to 78.3% in the period of this study. The share of people aged 85+ rose from 26.6% to 31.4%, and the authors observe a doubling of cases with prolonged dwindling at the end of their life. Despite their high need for care, 4 in 5 people lived in a private household in their last year of life, and 1 in 3 people lived alone. The authors' findings suggest a change in the volume of care need and in the types of care required. They have strong implications for care providers. **Abstract:** https://goo.gl/s29y1X

1. 'How many people will need palliative care in 2040? Past trends, future projections and implications for services,' *BMC Medicine*, published online 18 May 2017. [Noted in the 22 May 2017 issue of Media Watch (#513, p.11)] **Full text:** https://goo.gl/TP7U92

Noted in Media Watch 29 January 2018 (#548, p.7):

- *BMC PALLIATIVE CARE* | Online – 26 January 2018 – **'Palliative and end-of-life care research in Scotland 2006-2015: A systematic scoping review.'** The Scottish Government set out its 5-year vision to improve palliative care in its Strategic Framework for Action 2016-2021.[1] Areas highlighted for future research include palliative interventions for people with non-malignant illness and multimorbidity; physical and psychological symptom assessment and management; interventions to support carers; and bereavement support. **Full text:** https://goo.gl/CwMGZu

    1. 'Strategic Framework for Action on Palliative & End-of-Life Care: 2016-2021,' Scottish Government, December 2015. [Noted in the 21 December 2015 issue of Media Watch (#441, p.8)] **Download/view at:** http://goo.gl/CKePjU

N.B. Additional articles on palliative and end-of-life care in Scotland noted in the 20 November 2017 issue of Media Watch (#539, p.6).

Preparing to die behind bars: The journey of male inmates with terminal health conditions

JOURNAL OF CORRECTIONAL HEALTH CARE | Online – 20 June 2018 – While research has expanded on end-of-life care in and out of prison settings, to date there has been little research conducted on how inmates experience dying behind bars. Through collecting data during observation of facilitated advance care planning sessions, this qualitative study revealed four main themes: 1) Losing a piece of everything; 2) Not sure what to feel; 3) Where will I die; and, 4) Finding purpose in the midst of purposelessness. These themes characterize the central issues discussed by inmates as they considered death behind bars. As we seek to improve health care in prison settings, this study provides insight into how inmates view their dying process. **Abstract:** https://goo.gl/4Fx1cf

Psychological perspective on compassion in modern healthcare settings

JOURNAL OF MEDICAL ETHICS | Online – 28 June 2018 – Compassionate care is a foundation of the U.K.'s National Health Service (NHS). However, several high-profile inquiries into healthcare failures in the NHS suggest compassion is often absent in our hospitals. Ensuing policies mandate healthcare professionals to 'show more compassion' but, as the psychological evidence-base indicates, this instruction neglects the complexity of this social emotion. This paper applies the psychological research on compassion to modern healthcare settings with the aim of creating a better understanding of the pathways leading to uncompassionate care. A review of the empirical evidence suggests a range of psychological factors modulate compassion. In particular, the psychological literature indicates the human compassion system is adaptive, highly attuned to its environment. As such, a healthcare professional's ability to experience and display compassionate behaviour will be, in part, determined by the environment in which they practise; that is, aspects of the organisational environment will either facilitate or inhibit compassion. This paper argues that the typical organisational set-up of a modern healthcare setting seriously undermines compassionate care. Organisational features frequently associated with uncompassionate care include the understaffing of hospital wards, excessive working shift patterns and the dogged focus on achieving service efficiencies – each has been identified as contributing to the alarming breakdown of compassionate care at the centre of several healthcare failings. Policies focusing on culture change in the NHS neglect the growing psychological evidence base on compassion, but by applying a psychological understanding of compassion to healthcare settings, we can begin to adequately understand and address the real causes of uncompassionate care. **Abstract:** https://goo.gl/NPTnCp

Noted in Media Watch 28 Mat 2018 (#565, p.15):

- *PLOS ONE* | Online – 17 May 2018 – **'The colours and contours of compassion: A systematic review of the perspectives of compassion among ethnically diverse patients and healthcare providers.'** Synthesis of the literature identified the perspectives, facilitators and barriers of compassion in healthcare within different ethnic groups. Compassion was described as being comprised of healthcare provider virtues (honesty, kindness, helpful, non-judgment) and actions (smile, touch, care, support, flexibility) aimed at relieving the suffering of patients. **Full text:** https://goo.gl/LyayzV

Re-framing global palliative care advocacy for the sustainable development goal era: A qualitative study of the views of international palliative care experts

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 25 June 2018 – The World Health Assembly Palliative Care Resolution in 2014 and the inclusion of palliative care (PC) within the Sustainable Development Goals raised optimism that PC would no longer be a peripheral aspect of global health. However, no funding, accountability measures or indicators for PC development accompanied these policy developments. This risks health actors continuing to prioritize the attainment of better known, target-driven aspects of healthcare. Sixteen international PC experts were interviewed for their epistemic expertise. Participants were interviewed face-to-face or via Skype. Participants strongly supported the roll-out of national PC policies around the world for two reasons: 1) To ensure PC attracts national funding streams; and, 2) To attract global funding for PC. The absence of a global indicator for PC development was considered a severe impediment to the inclusion of PC within global efforts towards universal health care. Advocacy partnerships, using human rights approaches with economic "frames," were considered the most effective methods of influencing policymakers. PC represents a value proposition which is not currently being maximized by advocacy. Advocates should consider PC developmentally, focusing upon "key asks" for development and consider how PC can contribute to other international development priorities, in particular poverty reduction. **Abstract:** https://goo.gl/gYgf13

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 p.14.

Nurse practitioners as disruptive innovators in palliative medicine

JOURNAL OF PALLIATIVE CARE | Online – 29 June 2018 – As the population ages, the corresponding rise in people living with life-limiting illnesses will lead to a greater need for clinician experts in palliative medicine (PM). There are not enough physicians available to care for the growing number of patients, however. The authors believe that nurse practitioners (NPs) are well positioned to meet this demand. In this paper, they use the concept of disruptive innovations to provide support for their belief that NPs can, and should, take a larger role in PM. First, the authors describe how two general types of business models – solution shops and value-adding processes – can be applied to health care in general and PM specifically. Second, they describe the concept of disruptive innovations. Finally, the authors use these business models to explain how NPs are particularly well suited to disrupt the current business model of PM, thereby allowing more patients with life-limiting illness to receive the high-quality care they need. **Abstract:** https://goo.gl/Dg5D6y

Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis

PALLIATIVE MEDICINE | Online – 29 June 2018 – This review provides an evidence base and conceptual model to inform future research into patient empowerment for patients with advanced life-limiting illness. Being an empowered patient, when living with advanced life-limiting illness is different to the experience and meaning of empowerment for other patient groups. “Patient empowerment” emerges as a metaphor for all that enables people to maintain their self-identity until the very end of life. Considering the benefits of services and programmes designed to empower patients in other groups, further research is needed to ensure end-of-life care is optimally empowering. The authors propose that the themes of this review may provide a useful starting point to guide the assessment of existing services and development of a new dialogue surrounding patient participation in the design of services and interventions. **Abstract:** https://goo.gl/LYaYLi

Noted in Media Watch 23 May 2016 (#463, p.14):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 10 May 2016 – **‘The Patient Care Connect Program: Transforming health care through lay navigation.’** The Patient Care Connect Program (PCCP) is a lay patient navigation program, implemented by the University of Alabama at Birmingham Health System Cancer Community Network. The PCCP’s goal is to provide better health and health care, as well as to lower overall expenditures. The program focuses on enhancing the health of patients, with emphasis on patient empowerment and promoting proactive participation in health care. **Full text:** https://goo.gl/fz6ftT

Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness

PALLIATIVE MEDICINE | Online – 29 June 2018 – Of the 3,555 articles found, 20 were included in this review. The authors identified three themes in patients’ experiences with advance care planning (ACP): 1) “Ambivalence” refers to patients simultaneously experiencing benefits from ACP as well as unpleasant feelings; 2) “Readiness” for is a necessary prerequisite for taking up its benefits, but can also be promoted by the process of ACP itself; and, “Openness” refers to patients’ need to feel comfortable in being open about their preferences for future care towards relevant others. **Full text:** https://goo.gl/H5f4dk

World hospice & palliative care day
Voices for hospices

13 October 2018

https://goo.gl/sxz85U

Palliative care needs are everywhere. Where do we begin?

NEUROLOGY | Online – 27 June 2018 – The concept of palliative care (PC) in neurology continues to evolve; yet, the stigma about PC remains. Some may view offering PC to patients with serious neurologic conditions as a medical failure. Until recently, most clinicians have associated PC with end-of-life care (EoLC) for patients with malignancy. Fortunately, many have increasingly recognized that EoLC is an important aspect of care for patients with neurologic conditions. In recent years, the concept of PC has expanded further to include care that focuses on physical, psychosocial, intellectual, and spiritual needs, with the goal of improving quality of life for all patients with serious illness. Thus, PC may be appropriate during any phase of serious illness.[1] Many neurologic disorders (e.g., multiple sclerosis, stroke, amyotrophic lateral sclerosis, and Parkinson disease) fall within this framework. Neuro-PC has begun to emerge as a specialty to address these important needs of our patients and their families. **Abstract:** https://goo.gl/1nHaig

New European Academy of Neurology guideline on palliative care in multiple sclerosis

MEDSCAPE | Online – 26 June 2018 – Increasingly, palliative care (PC) is becoming a topic of interest and concern to neurologists all over the world. Delegates to the Congress of the European Academy of Neurology 2018 discussed PC as it relates to neurology in general – but also in the setting of multiple sclerosis (MS) in particular – as a guideline targeted to patients with severe MS was discussed. The new MS guideline [yet to be published] emphasizes the need for a multidisciplinary and multi-professional approach to care. For example, a PC team could include a neurologist, a nurse, a physiotherapist, and a social worker. **Full text:** https://goo.gl/uKKNrd

N.B. Selected articles on palliative care for people living with multiple sclerosis noted in the 17 October 2016 issue of Media Watch (#483, p.12).

1. 'Neuropalliative care: Priorities to move the field forward,' Neurology, published online 27 June 2018. Abstract: https://goo.gl/Sku19J

N.B. Additional articles on the role of palliative care in neurology noted in the 19 February 2018 issue of Media Watch (#551, p.8).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *THE AUSTRALIAN JOURNAL OF ANTHROPOLOGY* | Online – 22 June 2018 – **'"Old age is cruel": The right to die as an ethics for living.'** In debates over medically assisted dying right to die activists are often accused of embracing an unbridled neoliberal individualistic ethics that devalue life and reject notions of community and care. Through an ethnographic study of activists in North America and Australia, this article aims to complicate this point of view by showing how they are deeply invested in what it means to act morally in the world *vis-à-vis* their relationships with others and how they envisage this issue within an ethics of care. Although activists are often accused by opponents of delegitimising the ageing process and relying on atomised individual values, in depth interviews with right to die activists reveal complex, ambiguous and contradictory reflections on the ageing process as a dominant source of suffering while defending an ethics of care and life. In the end, this article argues that the right to die paradoxically constitutes an ethics for living. **Abstract:** https://goo.gl/n2Jdd2

- *BRITISH JOURNAL OF PSYCHIATRY*, 2018;213(1):393-395. **'Assessment of decision-making capacity in patients requesting assisted suicide.'** In this editorial, the authors argue that current attitudes toward terminally ill patients are generally too paternalistic, and that it is wrong to assume that patients suffering from mental health issues (including depression) cannot consent to assisted suicide. **Summary:** https://goo.gl/85YMfa

Cont.

- *ETHICS & MEDICINE*, 2018;34(2). **'Can euthanasia be classified as a medically beneficial treatment?'** Euthanasia – medical assistance in dying (MAiD), as it is known in Canada – has been advanced in popular debate as being a possibly better medical choice than living with significant suffering or diminishing dignity, particularly in palliative situations. However, this claim cannot be analyzed through the apparatus of medical science. Medical science, being limited to the physical world, is unable to investigate whether oblivion, heaven, hell, reincarnation, et cetera follow death and whether any or all of these possibilities are truly better than suffering on this side of death. According to the standards of medical practice, particularly those in Canada, a justification rooted in evidence-based medical science is necessary for an intervention to be considered licit medical care. MAiD does not currently – and inherently cannot in future – provide such a justification, unless medical science discovers a means to transcend death and investigate what follows. At present, death being synonymous with less suffering is only philosophical speculation. Thus, however else society decides to legislate euthanasia, it is not medically ethical and should not be administered as a medical intervention. **Abstract (available at ProQuest):** https://goo.gl/3dAfL8

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

Search Back Issues of Media Watch @ http://goo.gl/frPgZ5

PALLIMED
A Hospice & Palliative Medicine Blog

Media Watch: Behind the Scenes
http://goo.gl/XDjHxz

Media Watch: Access on Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/T2tCWF

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5

PALLIATIVE CARE NETWORK: https://goo.gl/YBP2LZ

PALLIMED: http://goo.gl/7mrgMQ

[Scroll down to ‘Media Watch by Barry Ashpole’; also ‘Media Watch: Behind the Scenes’ at https://goo.gl/6vdk9v]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/ZRngsv

[Scroll down to ‘Resource Collection’ and ‘Media Watch Barry Ashpole’]

Australia

PALLIATIVE CARE WESTERN AUSTRALIA: https://goo.gl/fCzNTL

[Scroll down to ‘International Websites’]

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: https://goo.gl/qw5ti8

[Click on ‘National Resources,’ scroll down to ‘Palliative Care Network Community’]

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2

[Scroll down to ‘Are you aware of Media Watch?’]

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD

[Scroll down to ‘Additional Resources’]

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC

[Scroll down to ‘International Palliative Care Resource Center hosts Media Watch’]

SASKATCHEWAN | Saskatchewan Medical Association: https://goo.gl/5cftPV

[Scroll down to ‘Palliative Care Network Community’]

Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE: https://goo.gl/KjrR6F

[March/April 2018 issue (Scroll down to ‘The homeless: A vulnerable population with poor access to palliative care.’]

HUNGARY | Magyar Hospice Alapítvány: https://goo.gl/L7D2hw

U.K. | Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

South America

Academia Nacional de Cuidados Paliativos (Brazil): https://goo.gl/b5CV31