

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

**'Value awareness: A new goal for end-of-life decision making' (p.11),
in *Medical Decision Making Policy & Practice*.**

U.S.A.

Survey lists nation's best, worst states for nursing home care

MCKNIGHT'S LONG-TERM CARE NEWS | Online – 4 February 2019 – An analysis of Medicare data ranks the nation's best states for nursing home care, according to organizers, and the last one to the party appears to have won the race. Hawaii ranks #1 on the list with an average quality ranking of 3.93...¹ On the flip side, Texas – a state in which experts have frequently complained about the reimbursement climate – ranks at the bottom of the list, with an average overall quality rating of 2.68. "When nursing home care becomes necessary, we would like to believe facilities in every state or community are the same. Unfortunately, like other healthcare services, that's not always the case," the authors write. Care.com ... experts compiled the rankings by analyzing 2017 Nursing Home Compare data and also surveying nearly 1,000 Americans with a family member entering skilled care. Rounding out the top five were Washington DC with a ranking of 3.89, Florida (3.75), New Jersey (3.75) and Colorado (3.74). Following Texas in the bottom of the rankings were Oklahoma (2.76), Louisiana (2.8), Kentucky (2.98) and Georgia (3.01). <http://bit.ly/2HTIOMX>

Specialist Publications

'Know legal differences between DNAR, POLST when counseling families about end-of-life care' (p.14), in *American Academy of Pediatrics News*.

'Disparities in place of death for patients with hematological malignancies, 1999 to 2015' (p.5), in *Blood Advances*.

'Racial/ethnic disparities in mortality: Contributions and variations by rurality in the U.S., 2012–2015' (p.8), in *International Journal of Environmental Research & Public Health*.

'Palliative care needs in oncology, cardiology, and neurology clinic patients in the U.S.' (p.9), in *Journal of General Internal Medicine*.

'Delays in palliative care referral among surgical patients: Perspectives of surgical residents across the state of Michigan' (p.10), in *Journal of Pain & Symptom Management*.

'What are social work students being taught about palliative care?' (p.13), in *Palliative & Supportive Care*.

1. 'Nursing Homes in America,' Care.com, January 2019. Download/view at: <http://bit.ly/2Gmn9cJ>

Noted in Media Watch 27 November 2017 (#540, p.3):

- CALIFORNIA | *The Mercury News* (San Jose) – 20 November 2017 – ‘**Nursing home residents have little access to palliative care, study says.**’ About 70% of nursing home residents are eligible for palliative care (PC), but don’t get the kind of support needed to relieve their symptoms and improve their quality of life (QoL). In a survey of 228 residents in three northern California nursing homes researchers found that 157 patients (68.8%) were eligible for specialized medical care that focuses on improving QoL for patients with serious illness.¹ Yet the report said none of the residents were receiving PC, and only two had hospice care. <https://bayareane.ws/2HZHIUu>
 1. ‘Palliative care eligibility, symptom burden, and quality-of-life ratings in nursing home residents,’ *JAMA Internal Medicine*, published online 20 November 2017. **Abstract (w. list of references):** <http://bit.ly/2S90lin>

Noted in Media Watch 21 August 2017 (#526, p.14):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 17 August 2017 – ‘**Palliative care consults in U.S. nursing homes: Not just for the dying.**’ Only four percent of all nursing home (NH) residents [in 54 NHs] received a palliative care (PC) consult during the study period. Two-thirds had short NH stays, and 81% of short- and 27% of long-stay consult recipients were on the Medicare skilled nursing facility (SNF) benefit at the time of initial consult. The high rates of SNF care and six-month survival among NH recipients of PC consults demonstrate the utility of these consults before Medicare hospice eligibility or use. **Abstract:** <http://bit.ly/2REfYyz>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | Colorado Public Radio (Centennial) – 4 February 2019 – ‘**More terminally ill people in Colorado are getting prescriptions to end their lives.**’ More terminally ill people in Colorado used legal prescription drugs to end their lives in 2018 than in the year before. A new report from the Colorado Department of Public Health & Environment found the number of prescriptions for the medications – either the drug Seconal or a cocktail of several others — rose 74% compared with 2017.¹ The state reported 125 people were prescribed medication to help end their lives last year. In 2017, that number was 72. The law allowing terminally ill people to use such medication was passed by Colorado voters in 2016. The Colorado End-of-Life Options Act permits physicians to prescribe the drugs to patients with six months or less to live. The law requires the patient to self-administer the medication, and also allows doctors to opt out of providing the care. In all, 66 doctors prescribed the drugs to patients last year. <http://bit.ly/2MRgYyz>
 1. ‘Colorado End-of-Life Options Act...’, Colorado Department of Public Health & Environment, February 2019. **Download/view at:** <http://bit.ly/2SAhruA>

International

End-of-life care in the U.K.

How to save hospices from collapse? Less medicine and some lessons from India

U.K. | *The Conversation* – 8 February 2019 – For the first time ever, one of Britain’s 200 independent hospices has closed its doors. St. Clare’s in Jarrow near Newcastle had been serving its community in the north east of England for 30 years, raising most of its annual costs of £2.2 million from local charitable giving. But after a trying period of medical under-staffing, concerns from independent regulator the Care Quality Commission and mounting financial problems, it has had no choice but to shut down. Senior sources familiar with hospice finances report that up to 50 more hospices may be in difficulties. The hospice movement took root outside the National Health Service (NHS) more than 50 years ago and quickly

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flourished. In the 1980s, ten new independent hospices were coming into being in the U.K. every year. By the early 1990s a Conservative government pledged to match hospice fundraising pound for pound. Since then, however, hospices have faced increasing cost pressures, of which the recent NHS pay rise is a typical example. Hospice managers want to implement it for their staff to keep in line with NHS practice, but it won't be covered by new government money. Costs have also been driven up by greater regulation and the demands of commissioners and quality inspections. As for the 50-50 funding pledge of the 1990s, it has never been met. <http://bit.ly/219eVHI>

Noted in Media Watch 28 January 2019 (#599, p.5):

- U.K. (England) | *The Shields Gazette* (South Shields) – 21 January 2019 – **'St. Clare's Hospice closes after more than 30 years.'** St. Clare's Hospice has closed after entering into insolvent liquidation. The Jarrow-based hospice has been providing specialist care and support to adults living with life-limiting illnesses and their families in South Tyneside since it opened in 1987. But now the independent hospice has announced it has closed following a decision to enter into insolvent liquidation. The charitable trust which runs the hospice has faced severe financial difficulties for a number of years, which has been compounded by a prolonged period of closure last year, leaving it insolvent. <http://bit.ly/213YvAi>

Specialist Publications

'A qualitative study of patient, caregiver and healthcare worker experiences of a palliative care programme in Kerala, India' (p.6), in *BMC Palliative Care*.

'The ageing and de-institutionalisation of death: Evidence from England and Wales' (p.8), in *Health Policy*.

'The prevalence of non-prescription cannabinoid-based medicines in British children's hospices: Results of a national survey' (p.11), in *Journal of Palliative Medicine*.

'Spiritual care in palliative care: A systematic review of the recent European literature' (p.12), in *Medical Sciences*.

'Palliative care in paramedic practice [in Australia]: A retrospective cohort study' (p.12), in *Palliative Medicine*.

'Beyond care burden: Associations between positive psychological appraisals and well-being among informal caregivers in Europe' (p.14), in *Quality of Life Research*.

'Assisted dying: Why the *British Medical Journal* does not poll members on nuanced ethical questions' (p.15), in *British Medical Journal*.

8,000 people die months after being rejected for disability benefit, Tories admit

U.K. (England, Northern Ireland & Wales | *The Daily Mirror* (London) – 6 February 2019 – Almost 8,000 people have died within six months of being rejected for a key disability benefit, Tory ministers admit. New figures reveal 7,990 people had an application for Personal Independence Payment (PIP) turned down – only to die within six months – since 2013. 3,680 of them were turned down less than three months before their death. People who had PIP turned down make up more than 10% of the 73,800 people, in total, who died within six months of registering a PIP claim. Department for Work & Pensions chiefs today insisted there was "no evidence" to suggest people died for the same reason they were trying to claim PIP. And those hit were only a small fraction of the millions of PIP claims since 2013. <http://bit.ly/2MR6TBS>

Noted in Media Watch 28 January 2019 (#599, p.4):

- U.K. (England, Northern Ireland & Wales) | *The Daily Express* (London) – 23 January 2019 – **'Change cruel law to help the dying: Scandal of terminally ill denied benefits.'** Charity Marie Curie said according to government figures, thousands of terminally ill patients were among the 17,000 who died awaiting decisions from 2013-2018. People can get fast-track access to tax-free Personal Independence Payments (PIP) at the highest rate if a doctor or nurse says they have less than six months to live. <http://bit.ly/2TG9zVx>

Carers quitting jobs from pressure

U.K. (England, Northern Ireland, Scotland & Wales) | BBC News – 5 February 2019 – More than 600 people a day leave their jobs because of the demands of being a carer, says research from a charity.¹ The pressures of looking after an elderly, ill or disabled relative have made almost half a million people quit their jobs in the U.K. in the past two years, says Carers UK. The report calls for more flexibility in the workplace for carers. The report estimates that almost five million people are trying to balance looking after relatives with working – up from about three million in 2011. An ageing population has pushed this increase – but the report says not enough employers are offering flexibility over working hours or taking leave. <https://bbc.in/2RHNN11>

1. 'Juggling work and unpaid care A growing issue,' Carers UK. **Download/view at:** <http://bit.ly/2ULOZ6p>

Pakistan severely lacks diagnostic, treatment and palliative care facilities

PAKISTAN | *The News International* (Islamabad) – 3 February 2019 – Cancer that has emerged as a major health threat in Pakistan has never been given due attention by the concerned government authorities as the facilities of screening and early detection of cancers along with treatment and even palliative care (PC) are not available in public sector healthcare facilities almost all across the country. Pakistan does not have National Cancer Registry in the absence of which it is hardly possible to assess the true nature of problem though according to estimates, well over 300,000 new individuals suffer from cancer every year in the country and the disease claims well over 50,000 lives every year. Data available at teaching hospitals show the existing pool of cancer patients is on the rise sharply. The most alarming fact is that in Pakistan, only minority of cancer patients are able to get treatment and that too in five to eight major cities of the country while population in smaller cities and peripheries do not have any screening or treatment facilities. It is also alarming that majority of cancer patients in the country are refused treatment due to limited capacity of cancer beds even in major cities and also there is a lack of facilities for even PC, the treatment to relieve symptoms and reduce pains caused by cancers. <http://bit.ly/2WEa848>

Noted in Media Watch 1 October 2018 (#583, p.16):

- *OCHSNER JOURNAL*, 2018;18(2):114. '**Palliative medicine in Pakistan: A developing country's perspective.**' In Pakistan, palliative medicine (PM) is not recognized as a discipline, so centers have not been established and physicians are not trained in palliative care (PC). According to the survey by the International Observatory on End-of-Life Care, Pakistan has the "least favorable ratio" for PC facilities, with only one service existing for a population of 157,935,000.¹ The medical curriculum taught in Pakistan has neither a dedicated course for PM nor a clinical rotation related to it. PM fellowship programs in Pakistan are lacking as well. The world dreads the future shortage of oncologists, but the situation could be even worse for Pakistan because of the absence of PM facilities and specialists. **Full text:** <http://bit.ly/2Dg809Z>
1. 'Mapping levels of palliative care development: A global view,' *Journal of Pain & Symptom Management*, 2008;35(5):469-498. **Full text:** <http://bit.ly/2Gplge6>



[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://bit.ly/2RPJy9b>

Specialist Publications

Disparities in place of death [in the U.S.] for patients with hematological malignancies, 1999 to 2015

BLOOD ADVANCES, 2019;3(3):333-338. More than 50,000 people die annually from hematological malignancies (HMs) in the U.S. Surveys suggest that only 1% of patients with cancer prefer an in-hospital death; most want to die at home. However, patients with HMs more frequently receive aggressive end-of-life care, and home hospice is seldom used. They are up to 4 times more likely to die in the hospital than those with solid tumors and, if referred to hospice, are more often enrolled in the last 24 hours of life. However, more comprehensive modern evaluation of place of death in the U.S. is limited, because prior research was based on Medicare data (therefore, only patients age ≥ 65 years) or institutional reporting. The authors, therefore, sought to evaluate changes in place of death for the HM population over time using a more inclusive data set, and to describe any associated healthcare disparities. In this study of all hematological cancer deaths over the past 17 years in the U.S., hospital deaths decreased by 30%, with a corresponding rise in home and hospice

facility deaths. Despite this overall trend, patients with HMs remained more likely to die in the hospital than patients with solid tumors. Hospital death has been associated with worse outcomes, with unmet symptom needs for patients and prolonged grief disorder for caregivers. **Full text:** <http://bit.ly/2D7hwvL>

Publishing Matters

'Updated Canadian Medical Association Journal policy on undisclosed competing interests' (p.17), in *Canadian Medical Association Journal*.

'Blacklisting or whitelisting? Deterring faculty in developing countries from publishing in standard journals' (p.17), in *Journal of Scholarly Publishing*.

'A preliminary study of alternative open access journal indexes' (p.17), in *Publishing Research Quarterly*.

Noted in Media Watch 4 February 2019 (/600, p.15):

- *PALLIATIVE MEDICINE* | Online – 30 January 2019 – **'Perspectives of bereaved relatives of patients with haematological malignancies concerning preferred place of care and death: A qualitative study.'** Although most people expressed a preference for home death, not all attained this. The influencing factors include disease characteristics, the occurrence and timing of discussions, family networks, and resource availability. Preferences were described as changing over time and some family members retrospectively came to consider hospital as the "right" place for the patient to have died. Others shared strong preferences with patients for home death and acted to ensure this was achieved. No patients died in a hospice, and relatives identified barriers to death in this setting. **Full text:** <http://bit.ly/2TIFRoH>

End-of-life care in the U.K.

What do patients and family-caregivers value from hospice care? A systematic mixed studies review

BMC PALLIATIVE CARE | Online – 8 February 2019 – It is not known which attributes of care are valued the most by those who experience hospice services. Such knowledge is integral to service development as it facilitates opportunities for continuous improvement of hospice care provision. Thirty-four studies highlighted that what patients and carers valued was generally context specific and stemmed from an amalgamation of hospice service components, which both individually and collectively contributed to improvements in quality of life. When the syntheses of qualitative and quantitative studies were viewed in isolation, the value placed on services remained relatively consistent, with some discrepancies evident in service availability. These were commonly associated with geographical variations, as well as differences

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in service models and timeframes. Through an overarching synthesis of the qualitative and quantitative evidence, however, notable variations and a more nuanced account of what people valued and why were more prominent, specifically in relation to a lack of social support for carers, disparate access to essential services, the underrepresentation of patients with a non-cancer diagnosis, and the dissatisfaction with the range of services provided. The findings of this review strengthen the existing evidence base and illuminate the underpinning elements of hospice care most valued by patients and their families. With large disparities in the availability of services, however, the underrepresentation of patients with non-malignant diseases and the limited evidence base demonstrating the adequate addressing of the social needs of carers, there continues to be considerable gap... **Full text:** <http://bit.ly/2tb0xUQ>

“Small small interventions, big big roles”

A qualitative study of patient, caregiver and healthcare worker experiences of a palliative care programme in Kerala, India

BMC PALLIATIVE CARE | Online – 4 February 2019 – Home-based palliative care (PC) is an essential resource for many communities. Doctors, nurses and volunteers have interdependent roles in providing PC to patients, including mentorship, training, patient care and advocating for patient needs. Volunteers also considered themselves to be mediators between families and the programme. Caregivers were mainly female and were caring for relatives. They have physically demanding, psychologically stressful and socially restrictive experiences of caregiving. They felt that the programme facilitated their role as caregivers by giving them training and support. Patients with long standing illnesses felt that the programme enabled them to become more independent and self-reliant. The local community supports the programme through economic contributions and offering practical assistance to patients. The salient features of this programme include the provision of regular holistic care through a team of doctors, nurses and patients. The programme was perceived to have improved the lives of patients and their caregivers. The involvement of volunteers from the local community was perceived as a strength of the programme, whilst simultaneously being a challenge. **Full text:** <http://bit.ly/2RFEK0X>

A pattern language of compassion in intensive care and palliative care contexts

BMC PALLIATIVE CARE | Online – 2 February 2019 – Grounded in the experiences and reflections of clinicians working in palliative care (PC) and critical care settings, the authors' findings show how compassion can be conceptualized, observed, and expressed in different ways; they also describe how compassion can become more explicit through modulations in personal, clinical and relational activities. The authors found that expressions of compassion in clinical settings were multidirectional; they could be expressed between any two or more people, including patients, their families, and members of the health-care team. In addition, expressions of compassion were responsive to emerging needs and circumstances, including clinical, social, cultural, procedural, and institutional. Expressions of compassion were reflected both in the states of mind of those involved, and in their actions, and included both practical skills and the intuitive expression and application of those skills within a given interaction. Compassion was conveyed through a holistic and integrative approach to care and professional practice. Expressions of compassion required being present to others' experiences, connectedness, honesty, and accepting of them. These multiple expressions of compassion were identified in both critical care and PC settings, and in patient-clinician, learner-preceptor, and between-clinician interactions – this suggests that compassion is not discipline- or relationship specific, but rather, emerges in multiple contexts between many different actors. A key finding from this study was that compassion does not yield well to taxonomic definitions; exceptions and variations confound a single concrete definition. **Full text:** <http://bit.ly/2t4bEyT>

Assisted ventilation in motor neurone disease during inpatient palliative care: Barriers and utilisation

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 2 February 2019 – An increasing number of patients with motor neuron disease (MND) in the U.K. and Ireland use assisted ventilation, and a small proportion of these use long-term tracheostomy ventilation (TV). NICE guidelines recommend that patients with MND should routinely receive specialist palliative care input. The aim of this study was to establish the extent to which hospices and specialist palliative care units (SPCUs) in the U.K. and Ireland currently manage patients with MND using assisted ventilation especially TV and to identify any associated barriers. A minority of U.K. and Irish hospices/SPUs provide support to TV MND patients and few units currently have management or admission policies for this cohort of patients. Survey respondents indicated a lack of appropriate expertise and experience. Further exploration of these barriers is required to establish how to optimise care for TV MND patients in this setting. **Abstract:** <http://bit.ly/2G6Q6KF>

Palliative care provision for patients with advanced chronic obstructive pulmonary disease: A systematic integrative literature review

COPD: JOURNAL OF CHRONIC OBSTRUCTIVE PULMONARY DISEASE | Online – 4 February 2019 – Although chronic obstructive pulmonary disease (COPD) is recognized as being a life-limiting condition with palliative care (PC) needs, PC provision is seldom implemented. The disease unpredictability, the misconceptions about PC being only for people with cancer, and only relevant in the last days of life, prevent a timely integrated care plan. This systematic review aimed to explore how PC is provided in advanced COPD and to identify elements defining integrated PC. Of the 458 titles, 24 were eligible for inclusion. Experiences about advanced COPD, PC timing, service delivery and PC integration emerged as main themes, defining a developing taxonomy for PC provision in advanced COPD. This taxonomy involves different levels of care provision and integrated care is the last step of this dynamic process. Furthermore, PC involvement, holistic needs' assessment and management and advance care planning have been identified as elements of integrated care. This literature review identified elements that could be used to develop a taxonomy of PC delivery in advanced COPD. Further research is needed to improve our understanding on PC provision in advanced COPD. **Abstract:** <http://bit.ly/2Sd99ck>

Noted in Media Watch 22 October 2018 (#586, p.9):

- *BMC PALLIATIVE CARE* | Online – 15 October – ‘**Attitudes to specialist palliative care and advance care planning in people with chronic obstructive pulmonary disease: A multi-national survey of [Australian] palliative and respiratory medicine specialists.**’ Respiratory doctors reported being comfortable providing a palliative approach and acknowledged the role of both specialist palliative care and advance care planning, yet in reality people with advanced obstructive pulmonary disease (COPD) rarely access these elements of care. Additionally, current models of care for people with COPD were considered inadequate and fragmented. **Full text:** <http://bit.ly/2BnwEFh>

Noted in Media Watch 24 September 2018 (#582, p.9):

- *CHRONIC RESPIRATORY DISEASE* | Online – 16 September 2018 – ‘**Chronic obstructive pulmonary disease patients in need of palliative care: Identification after hospitalization through the surprise question.**’ Few patients suffering from chronic obstructive pulmonary disease (COPD) are referred to a palliative care (PC) team. There is need for a simple and easily applicable tool to identify those patients who would benefit from referral to a PC team. The aim of this study was to determine if the surprise question (SQ) “Would I be surprised if this patient dies within 12 months?” in a subset of recently hospitalized COPD patients identifies those subjects. **Full text:** <http://bit.ly/2WGejgG>



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The ageing and deinstitutionalisation of death: Evidence from England and Wales

HEALTH POLICY | Online – 2 February 2019 – Increasingly, age of death is postponed until very old age, and care of those who are dying is challenged by medical co-morbidities and the presence of dementia. Although most people would prefer to die at home, currently in England and Wales only about 20% of those aged 65 years and over die at home, and this proportion falls to about 10% among those aged over 85 years. To explore recent and likely future trends in age and place of death, mortality statistics from 2006 to 2013 were analysed and projected to 2050 using age- and gender-specific rates. Results confirmed recent increasing age at death and indicated a trend for increasing proportions of older people to die at home. Projections indicated large increases in home-based deaths, particularly for men aged 65 and over. Consistent with people's wishes, there may be a partial return to the view that dying at home is a normal experience. Resource allocations are likely to need to shift to support people dying at home and their formal and informal carers. **Abstract:** <http://bit.ly/2DkdP61>

Racial/ethnic disparities in mortality: Contributions and variations by rurality in the U.S., 2012–2015

INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH & PUBLIC HEALTH | Online – 2 February 2019 – This report documents and extends epidemiologic descriptions of mortality disparities existing at intersections between place and race/ethnicity. This opens the door for work to identify and address the unique and shared factors underlying these differences and disparities. Specific attention to the interplay of social and individual determinants of health over time, as health is shaped by the structures and social ecologies of different places is warranted. Such research could identify place-specific conditions influencing how race/ethnicity is experienced and operates in expanding or limiting health opportunities. Moreover, characterizing social processes creating different population health trajectories is essential to address the effects of forces for which rural and urban categories and sub-categories may be proxies (e.g., state and local political, economic, and health infrastructures, policies, and practices; neighborhood, school, and workplace conditions; risk exposure levels etc.). This in turn, could suggest interventions to alter context specific factors driving racial/ethnic disparities in the leading causes of death that are more potent and relevant than current practice. **Full text:** <http://bit.ly/2Gsdvp0>



Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 February 2019 – **‘Improving end-of-life care for diverse populations: Communication, competency, and system supports.’** While disparities in end-of-life care (EoLC) have been well-documented, explanations for the persistence of disparities are less clear. This study sought to examine diverse perceptions of EoLC, especially regarding how medical professionals can better serve all populations. Three major themes emerged: 1) Clear, comprehensive, and culturally relevant provider-patient communication regarding serious illness; 2) Provider characteristics and competency; and, 3) Health system supports and barriers. **Abstract:** <http://bit.ly/2MTIATX>

N.B. Selected articles on ethnic and racial disparities in the provision and delivery of palliative and end-of-life care in the U.S. noted in 4 February 2019 issue of Media Watch (#600, p.3).

Families' experiences [in The Netherlands] with end-of-life care in nursing homes and associations with dying peacefully with dementia

JOURNAL OF THE AMERICAN MEDICAL DIRECTORS ASSOCIATION | Online – 1 February 2019 – Data were collected at 34 Dutch nursing homes and included 252 reports from bereaved family members of nursing home residents with dementia. Families' reports of unpleasant experiences translated into two

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themes: 1) Neglect; and, 2) Lack of respect. Neglect involved facing inaccessibility, disinterest, or discontinuity of relations, and negligence in tailored care and information. Lack of respect involved perceptions of being purposefully disregarded, an insensitive approach towards resident and family, noncompliance with agreements, and violations of privacy. Unpleasant experiences with end-of-life care (EoLC) were negatively associated with families' perceptions of the resident dying peacefully. Families' assessment of their relative dying peacefully was positively associated with satisfaction with EoLC and decision making. Humane and compassionate care and attention from physicians and other staff for resident and family may facilitate recollections of a peaceful death. **Abstract (inc. link to references):** <http://bit.ly/2GtSMky>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 8 February 2019 – ‘**Advance care plans in dementia: User-centred design.**’ Historically, dementia has not been recognised as a life-limiting condition or one that may benefit from a palliative approach to its care. There are many challenges in providing palliative and end-of-life care to this group of people, some of which may be reduced through advance care planning (ACP) to support people with dementia to have a greater influence on their care at end of life. The objective of this project was to involve people with dementia and their family carers in co-design of ACP guide and template to prepare for further study related to communication processes in ACP. **Abstract:** <http://bit.ly/2So5Sav>

Extract from Annual Report on Progress Against Cancer

Palliative interventions beneficial among patients undergoing potentially curative treatment of blood cancer

JOURNAL OF CLINICAL ONCOLOGY | Online – 31 January 2019 – Building on prior research showing the benefits of early initiation of supportive care, including palliative care (PC), in patients with advanced cancer, a new study ... looked at the approach in 160 people with hematologic malignancies undergoing potentially curative hematopoietic stem-cell transplantation.¹ The study randomly assigned people to routine transplantation care or transplantation care with integrative supportive and PC. At the start of the study and at 6 months after transplantation, the investigators assessed quality of life, anxiety, and symptom burden, among other factors. The researchers found that patients in the intervention arm (integrated PC) had lower depression symptoms and lower post-traumatic stress disorder symptoms, but there was no benefit for quality of life or anxiety. On the basis of this study, incorporating inpatient PC into routine transplantation could lead to decreased psychological distress that typically persists 6 months after the transplantation. **Full text:** <http://bit.ly/2HXMFY9>



1. 'Effect of inpatient palliative care during hematopoietic stem-cell transplant on psychological distress 6 months after transplant: Results of a randomized clinical trial,' *Journal of Clinical Oncology*, published online 19 September 2017. [Noted in 9 October 2017 issue of Media Watch (#533, p.9)] **Full text:** <http://bit.ly/2TxhBjr>

N.B. 'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline,' *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in 31 October 2016 issue of Media Watch (#486, p.7)] **Full text:** <http://bit.ly/2DjSsSh>

Palliative care needs in oncology, cardiology, and neurology clinic patients in the U.S.

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 7 February 2019 – The Institute of Medicine's 2014 report calls for all clinicians to provide symptom-oriented palliative care (PC) to patients, especially for the growing population of older adults with advanced illness.¹ Oncology, cardiology, and neurology professional societies all recommend their members complement usual disease-oriented care with symptom-oriented PC services for patients with advanced illness. However, the proportion of oncology, cardiology, and neurology patients who have advanced illness and are most likely to benefit from symptom-oriented PC is unclear. **Introductory paragraph (w. list of references):** <http://bit.ly/2E0tU2i>

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1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in 22 September 2014 issue of Media Watch (#376, p.4)] **Full report:** <http://bit.ly/2GeVXNO>

Can “medical futility” conflicts be mediated?

JOURNAL OF MEDICAL LAW & ETHICS, 2018;6(1):41-53. Mr. Justice Francis ended his judgment in *Great Ormond Street Hospital v Yates, Gard and Gard* with the recommendation that “mediation should be attempted in all cases such as this one.” Although this gave the impression that mediation would be unquestionably beneficial in the Gard case and other “medical futility” cases where the patient is incompetent, the author contends this is not as straightforward as it might at first appear. With the general absence of a middle ground and with the law in such cases frequently on doctors’ side, mediation’s potential for a satisfactory resolution of medical futility conflicts is arguably limited. **Abstract:** <http://bit.ly/2Dpp50W>

N.B. Selected articles on the Charlie Gard case noted in 3 December 2018 issue of Media Watch (#592, pp.12-13).

Delays in palliative care referral among surgical patients: Perspectives of surgical residents across the [U.S.] state of Michigan

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 February 2019 – This qualitative study identifies critical barriers to palliative care (PC) referral among seriously-ill surgical patients from the perspective of surgical residents. Four dominant themes of resident-perceived barriers ... were identified: 1) Challenges with prognostication; 2) Communication barriers; 3) Respect for the surgical hierarchy; and, 4) Surgeon mentality. Residents consistently expressed challenges in predicting patient outcomes, and verbalizing this to both attendings and families augmented this uncertainty in seeking PC services. Communicative challenges included managing discordant provider opinions and the stigma associated with PC. Finally, residents perceived that an attending surgeon’s decisive authority and mentality negatively influenced the delivery of PC services. Among resident trainees, unpredictable patient outcomes led to uncertainty in the timing and appropriateness of PC referral, and further complicated communicating plans of care. Residents perceived and relied on the attending surgeon as the ultimate decision maker, wherein the surgeon’s sense of responsibility to the patient was identified as a significant barrier to PC referral. **Abstract:** <http://bit.ly/2E2cTEY>

Emergency department-based palliative interventions: A novel approach to palliative care in the emergency department

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 February 2019 – Patients with palliative care (PC) needs were identified using an abbreviated 5-question version of the screen for palliative and end-of-life care needs in the emergency department (ED) – 5-SPEED. These patients were then automatically flagged for an ED-based palliative intervention (EPI) as determined by their identified need. The primary outcome was the prevalence of PC needs among patients with active cancer. Secondary outcomes were the rate of EPI services successfully delivered to ED patients with unmet PC needs, ED length of stay (LoS), and repeat ED visits within the next 10 days. Of the 1,278 patients with active cancer, 817 (63.9%) completed the 5-SPEED screen. Of the patients who completed the screen, 422 patients (51.7%) had one or more unmet PC needs and 167 (39.6%) received an EPI. There were no differences in ED LOS or 10-day repeat ED visit rates between patients who did or did not receive an EPI. This ED-based intervention successfully screened for palliative needs in cancer patients and improved access to specific palliative services without increasing ED LOS. **Abstract:** <http://bit.ly/2Suram4>



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

The prevalence of non-prescription cannabinoid-based medicines in British children's hospices: Results of a national survey

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 February 2019 – Anecdotal evidence suggests that cannabinoid-based medicines (CBMs), specifically cannabis oil (CO), are being used by families with increasing frequency to manage distressing symptoms. The use of most non-prescription CBMs in the U.K. remains illegal. Forty children's hospices from across the four countries of the U.K. responded to the survey, representing 74% of British children's hospices. About 87.5% of hospices knew of children who use CO therapeutically. Sixty-nine percent of those hospices have received requests to administer CO during an episode of care. Approaches by organizations around CO management varied across the sectors, including arrangements for storage, administration, and recording of its use. Hospices highlighted how the lack of available guidance made decision making more challenging. Only a third of responding organizations routinely questioned families about the use of cannabis when prescribing medicines. Despite recognizing the use of CO, many hospices are unable to support it. There is a need for clear guidelines on how hospices should approach the care needs of children, allowing hospices to meet the needs of children who use CO, and families in a safe, consistent, and relevant way, safeguarding all children, families, and professionals within the organization. **Abstract:** <http://bit.ly/2MS0YMF>

N.B. Selected articles on cannabinoids in palliative medicine noted in the 21 January 2019 issue of Media Watch (#598, pp.9-10).

Value awareness: A new goal for end-of-life decision making

MEDICAL DECISION MAKING POLICY & PRACTICE | Online – 1 February 2019 – The principal policy tool for respecting the preferences of patients facing serious illnesses that can prompt decisions regarding end-of-life care is the advance directive (AD) for healthcare. AD policies, decision aids for facilitating ADs, and clinical processes for interpreting ADs all treat patients as rational actors who will make appropriate choices, if provided relevant information. The authors review barriers to following this model, leading them to propose replacing the goal of rational choice with that of value awareness, enabling patients (and, where appropriate, their surrogates) to be as rational as they can and want to be when making these fateful choices. The authors propose approaches, and supporting research, suited to individuals' cognitive, affective, and social circumstances, resources, and desires. **Abstract (w. list of references):** <http://bit.ly/2MPZfaR>



Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 February 2019 – '**A qualitative study of serious illness conversations in patients with advanced cancer.**' Twenty-five conversations conducted by 16 clinicians were evaluated. The median conversation duration was 14 minutes (range 4-37), with clinicians speaking half of the time. Analyses demonstrated five key themes: 1) Supportive dialogue between patients and clinicians; 2) Patients' openness to discuss emotionally challenging topics; 3) patients' willingness to articulate preferences regarding life-sustaining treatments; 4) Clinicians' difficulty in responding to emotional or ambiguous patient statements; and, 5) Challenges in discussing prognosis. **Abstract:** <http://bit.ly/2DeM52B>
- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 4 February 2019 – '**End-of-life care planning: The importance of older adults' marital status and gender.**' Health status and behaviors are known to differ across marital status groups, yet research on end-of-life care (EoLC) planning has only compared married and unmarried persons, overlooking differences between divorced and widowed individuals, by gender. This study examined marital status differences in EoLC planning by comparing the likelihood of discussions about EoLC, designation of medical durable power of attorney for healthcare decisions, and completion of a living will for married, divorced, and widowed older adults, by gender. **Abstract:** <http://bit.ly/2t3XXzU>

Cont.

- *SUPPORTIVE CARE IN CANCER* | Online – 8 February 2019 – ‘**Barriers and facilitators to shared decision-making in oncology: A systematic review of the literature.**’ The identified themes for barriers to shared decision-making (SDM) were uncertainty in the treatment decision, concern regarding adverse effects, and poor physician communication. Themes for facilitators for SDM included physician consideration of patient preferences, positive physician actions and behaviors, and use or encouragement of support systems. As SDM gains use within oncology practice, understanding key influences will allow for more effective implementation of strategies to increase patient engagement and improve care and value in the treatment process. **Abstract:** <http://bit.ly/2TH1qjB>

Spiritual care in palliative care: A systematic review of the recent European literature

MEDICAL SCIENCES | Online – 7 February 2019 – Many studies on spiritual care in palliative care (PC) are performed in the U.S., leaving other continents unexplored. The objective of this systematic review is to map the recent studies on spiritual care in palliative care in Europe. 53 articles were included. Spiritual care was seen as attention for spirituality, presence, empowerment, and bringing peace. It implied creative, narrative, and ritual work. Though several studies reported positive effects of spiritual care, like the easing of discomfort, the evidence for spiritual care is low. Requirements for implementation of spiritual care in PC were developing spiritual competency, including self-reflection, and visibility of spirituality and spiritual care, which are required from spiritual counselors that they participated in existing organizational structures. Future studies are necessary to develop appropriate patient outcomes and to investigate the effects of spiritual care more fully. **Abstract:** <http://bit.ly/2GA8jzp>

N.B. Click on pdf icon to access full text.

Analysis of caregiver burden in palliative care: An integrated review

NURSING FORUM | Online – 8 February 2019 – The inclusion of caregivers in a holistic care approach represents a basic principle in palliative care (PC). However, many PC professionals have a lack of understanding of difficulties or unmet needs among caregivers. To enhance the quality of life of caregivers and the quality of care for patients, healthcare professionals should be better informed about the constructs of caregiver burden. The aim of this study is to synthesize the concept of caregiver burden in PC, providing implications for the caregivers and their support systems. From this literature search, 66 articles from 1998 to 2018 are located. After data collection is completed, the two authors independently evaluate the quality of studies published before 1 September 2018. The caregiver burden is then redefined with its attributes, antecedents, consequences, empirical referents, and facilitators. It is recommended that the multidimensional concept of caregiver burden in PC be measured by considering caregiver characteristics and the caregiving context. **Abstract:** <http://bit.ly/2E1IZRc>

Palliative care in paramedic practice [in Australia]: A retrospective cohort study

PALLIATIVE MEDICINE | Online – 5 February 2019 – Paramedics may be involved in the care of patients experiencing a health crisis associated with palliative care (PC). However, little is known about the paramedic’s role in the care of these patients. A total of 4,348 cases met inclusion criteria. The most common paramedic assessments were “respiratory” (20.1%), “pain” (15.8%) and “deceased” (7.9%); 74.4% were transported, with the most common destination being a hospital. Of those with pain as the primary impression, 359 (53.9%) received an analgesic, morphine, fentanyl or methoxyflurane, and 356 (99.2%) were transported following analgesic administration. Resuscitation was attempted in 98 (29.1%) of the 337 cases coded as cardiac arrest. Among non-transported cases, there were 105 (9.6%) cases where paramedics re-attended the patient within 24 hours of the previous attendance. Paramedics have a significant role in caring for patients receiving PC. These results should inform the design of integrated systems of care that involve ambulance services in the planning and delivery of community-based PC. **Abstract:** <http://bit.ly/2Shs59Z>

What are social work students [in the U.S.] being taught about palliative care?

PALLIATIVE & SUPPORTIVE CARE | Online – 4 February 2019 – Palliative social workers have taken steps to increase the numbers of social workers trained and competent to deliver effective psychosocial palliative care (PC). Despite these developments, masters of social work (MSW) programs have only begun to develop curricula preparing students for entry-level practice. This study sought to determine the type and extent of content areas included in MSW courses dedicated to PC or with content related to PC practice. Of the 105 participating programs that responded to the survey, 42 submitted 70 syllabi for courses with at least some PC content. There were 29 topics identified. The most common topic was grief, loss, and bereavement, followed closely by behavioral and mental health issues, and supporting family and friends; cultural perspectives and advance care planning (ACP) were also common topics. For the 10 syllabi from courses dedicated to PC, supporting family was the most common topical area, followed closely by interprofessional practice and ACP. Although there are many challenges to introducing PC content into MSW programs, including unqualified faculty and competing course material and electives of equally compelling content, there are model curricula for dedicated PC courses. **Abstract (w. list of references):** <http://bit.ly/2WGacAI>

Pediatric palliative care

Gaps in the implementation of shared decision-making: Illustrative cases

PEDIATRICS | Online – 5 February 2019 – Shared decision-making (SDM) has emerged as the preferred decision-making model in the clinician-patient relationship. Through collaboration, SDM helps to facilitate evidence-based medical decisions that are closely aligned with patient or surrogate preferences, values, and goals. How to implement SDM in clinical pediatric practice, however, remains elusive, in part because SDM in pediatrics is complicated by the involvement of parents as a special class of surrogate decision-maker. A provisional framework for the process of SDM in pediatrics was recently proposed by Opel to help facilitate its implementation. To identify aspects of the framework that require refinement, the authors applied it across a diverse range of clinical cases from multiple pediatric specialties. In doing so, several questions surfaced that deserve further scrutiny: 1) For which medical decisions is consideration of SDM required?; 2) What is considered medically reasonable when there is variability in standard practice?; 3) Can an option that is not consistent with standard practice still be medically reasonable?; 4) How should public health implications be factored into SDM?; 5) How should variability in preference sensitivity be approached?; 6)

How should the developing autonomy of adolescents be integrated into SDM?; and, 7) How should SDM address parental decisional burden for emotionally charged decisions? The authors conduct a brief analysis of each question raised to illustrate key areas for future research. **Abstract:** <http://bit.ly/2Sd2xe0>

A mixed-methods exploration of pediatric intensivists' attitudes toward end-of-life care in Vietnam

JOURNAL OF PALLIATIVE MEDICINE | Online – 6 February 2019 – Although the need for palliative care (PC) is gaining recognition in Southeast Asia, knowledge about how decisions are made for children near the end of life remains sparse. Sixty-eight providers (33 physicians and 35 nurses) completed a quantitative survey, and 18 participated in interviews. Qualitative data revealed three overarching themes with numerous sub-themes and supporting quotations. The findings of this study indicate a need to strengthen PC training, increase family involvement in decision making, implement standardized and official do-not-resuscitate documentation, and expand pediatric hospice services at the individual, hospital, and national levels in Vietnam. **Abstract:** <http://bit.ly/2HY3KBn>

Cont. next page



Would this article be of interest to a colleague?

Related

- *AMERICAN ACADEMY OF PEDIATRICS NEWS* | Online – 7 February 2019 – ‘**Know legal differences between DNAR, POLST when counseling families about end-of-life care.**’ The physician in the patient’s medical home usually ... is well-suited to discuss end-of-life care, including DNAR orders. When developmentally appropriate, the child should be part of these conversations. Historically, these documents have been institution-limited, meaning they only covered the patient while in a single setting (e.g., a specific hospital or long-term care facility). Thus, a patient’s nursing home DNAR order might not be recognized at the local hospital. Further, it was common that emergency medical service providers did not recognize the order. **Full text:** <http://bit.ly/2RIWkSq>
- *ARCHIVES OF DISEASE IN CHILDHOOD* | Online – 31 January 2019 – ‘**Parallel planning and the paediatric critical care patient.**’ A growing number of children with life-limiting conditions (LLCs) are being cared for in paediatric critical care (PCC) settings. Children with LLCs admitted to PCC are at a high risk of developing complications and many die after prolonged admissions. Relatively few of these patients and their parents or carers have had documented discussions about their wishes for care in the event of a serious clinical deterioration before admission to PCC. There is a need for improved understanding of 1) How parents arrive at decisions regarding what is best for their child at times of critical illness, and 2) The role of parallel planning and advance care plans in that process. This review examines the complexities of decision-making in children with LLCs who are admitted to PCC settings. **Abstract:** <http://bit.ly/2Ss4Fho>
- *JOURNAL OF CHILD NEUROLOGY* | Online – 15 January 2019 – ‘**Parents’ experiences of information and decision making in the care of their child with severe spinal muscular atrophy: A [Danish] population survey.**’ Thirty-four parents of 21 children participated. Eleven were non-bereaved and 23 were bereaved parents. All stated healthcare staff did not take any decisions without informing them. A proportion indicated, however, that they were not informed about what spinal muscular atrophy entails (32%), possible treatment options (18%), or the fact that their child would have a short life (26%) or that death was imminent (57%). Most of the bereaved parents who had wishes concerning how and where their child would pass away had their wishes fulfilled. **Abstract:** <http://bit.ly/2HPPkDa>

Beyond care burden: Associations between positive psychological appraisals and well-being among informal caregivers in Europe

QUALITY OF LIFE RESEARCH | Online – 4 February 2019 – The burden of caring for a family member or friend can have a negative impact on caregiver health and well-being, yet caring can also have positive consequences. Understanding the factors that may enhance caregiver well-being is merited. 36,908 respondents took part in the European Quality of Life Survey, with 4,171 (11%) identifying as frequent carers. While frequent caregivers reported lower well-being compared to the remaining population, most were happy with the amount of time spent caring. The authors’ model explained approximately 32% of variance in well-being scores. After examining the role of known risk factors, all positive psychological appraisals were associated with higher well-being. In order of magnitude these were optimism, perceived autonomy, sense of purpose, resilience, and perceived levels of social inclusion. Self-rated health was the strongest predictor of well-being while female carers and those with high levels of various burden measures reported lower well-being. Findings suggest that caregiver well-being is influenced by more than simply the burden of care. As well as attempting to reduce burden, interventions aimed at supporting caregivers could focus on fostering more positive appraisals to enhance well-being in this group. **Abstract (w. list of references):** <http://bit.ly/2S6WEzI>

Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 4 February 2019 – ‘**Healing experience for family caregivers after an intensive care unit death.**’ The purpose of this study was to describe and interpret the experience of healing for family caregivers six weeks following the death of a loved one in the ICU. Seven themes were interpreted from the data: 1) Searching for clarity from a time of uncertainty; 2) Riding an emotional rollercoaster; 3) Seeking peace in one’s decisions; 4) Moving forward with each new day; 5) Taking comfort in the memories; 6) Valuing layers of support; and, 7) Discovering life on one’s own. **Abstract:** <http://bit.ly/2GdCOXN>

Personal relationships during end-of-life care: Support staff views of issues for individuals with intellectual disability

RESEARCH IN DEVELOPMENTAL DISABILITIES, 2019;87(4):21-30. Life expectancy for persons with intellectual disability has increased dramatically over the past decade, which has seen an associated rise in the need for end-of-life (EoL) care. However, little is known regarding how EoL affects the individual's personal relationships with family, friends and staff. Interviews were undertaken with 35 disability support workers from four rural and two metropolitan locations in New South Wales and Queensland, Australia. Analysis identified three key thematic areas: 1) Relationships with family, relationships with friends and staff roles; 2) Relationships with friends had two sub-themes of "positive experiences" and "negative experiences"; and, 3) Staff roles had two sub-themes of "loss of contact" and "default decision making." The frequency of family contact was not reported as increasing or decreasing following the diagnosis of a life-ending illness and during an individual's EoL. A lack of counselling support was noted as potentially impairing the individual's friends' ability to cope with death. Staff also reported a number of concerns regarding how their relationships with the individual changed, particularly when EoL entailed potential movement of the individual with intellectual disability to a new residential setting. **Abstract:** <http://bit.ly/2TASJav>

N.B. Selected articles on palliative and end-of-life care for people living with intellectual and developmental disabilities noted in 26 November 2018 issue of *Media Watch* (#591, pp.13-14).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BRITISH MEDICAL JOURNAL* | Online – 6 February 2019 – '**Assisted dying: Why the British Medical Association does not poll members on nuanced ethical questions.**' The Association has never asked its entire membership of 158,000 U.K. doctors for their views on physician assisted dying. Although this might sound counterintuitive, such nuanced, complex, and potentially divisive ethical issues do not lend themselves to decision making through direct polling or surveys. Instead, we have clearly defined and longstanding deliberative and democratic processes through which we typically make policy. Apart from concerns about the accuracy of survey results and the potential for voters at either end of the spectrum of opinion to organise swing voting in their direction, to focus on whether we should poll members on assisted dying is to miss a far more important point: the professionalism and expertise that has been employed in drafting our policy on end-of-life care and assisted dying. **Introductory paragraphs:** <http://bit.ly/2GbOaQV>
- *HEALTHCARE POLICY*, 2018;14(2):59-67. '**Completion of medical certificates of death after an assisted death: An environmental scan of practices [in Canada].**' Policies and practices have been developed to operationalize assisted dying processes in Canada. This project utilized an environmental scan to determine the spectrum of assisted death reporting practices and medical certificate of death (MCD) completion procedures both nationally and internationally. Findings suggest medically assisted dying (MAiD) is represented on the MCD inconsistently nationally and internationally. Related factors include the specifics of local assisted death legislation and variations in death-reporting legislation, variation in terminology surrounding assisted death and designated oversight agency for assisted dying reporting. **Abstract:** <http://bit.ly/2RFm5D3>

Related

- *HEALTHCARE POLICY*, 2018;14(2):6-9. '**Illuminating the consequences of policy change.**' The ripple effects of major policy changes are difficult to predict in advance. That is why the ability to track consequences of decisions – intended and unintended – is an important role of health services and policy research. Whatever one's views on medical assistance in dying (MAiD), there is consensus on the need to understand how often, and in what circumstances, such deaths take place. Being able to track deaths in a consistent way also matters. Comparisons between different population groups, across regions of the country, and with other nations can be helpful in illuminating the effects of this policy and its application. **Full text:** <http://bit.ly/2DSvwe1>

Cont.

- *MEDICAL HUMANITIES* | Online – 7 February 2019 – ‘**The people speak: Social media on euthanasia/assisted dying.**’ In New Zealand, aiding and abetting a person to commit suicide or euthanasia even with consent is unlawful. The introduction of a third Bill on assisted dying to the House of Representatives following a high-profile court case afforded an opportunity for examining how assisted dying was discussed in the public sphere. The authors report on a discourse analysis of a selection of social media to illustrate the ways in which citizens participate in the voluntary euthanasia debate. Social media postings represent the voices of ordinary citizens who may not participate in formal public consultation processes. Based on the authors’ analysis, the assignment of binary conclusions about public opinion is simplistic and fails to adequately represent the intricacies of public debate. Contributors’ posts reveal deeply held socio-cultural values, as well as tensions about the relationship between citizens and the apparatus of government. **Abstract:** <http://bit.ly/2SI99Yb>
- *MORTALITY* | Online – 4 February 2019 – ‘**Representations of palliative care, euthanasia and assisted dying within advocacy declarations.**’ It is well known that there are disagreements between the proponents of palliative care (PC) and of euthanasia or assisted dying, often with little common ground, shaping the end-of-life discourse internationally. Advocacy documents or “declarations” constitute a significant feature of this discourse. The aim of this study was to explore the content of such declarations and to focus on what they can tell us about PC and assisted dying and their dispositions towards one another. 104 declarations were identified and included in the study, covering the period 1974 to 2017. The authors classified them based on their primary purpose: those with the goal of advocating for PC services, education and research were grouped under “palliative care declarations”; those with the primary objective of advocating for or against euthanasia/assisted dying were classified as “euthanasia/assisted dying declarations.” Their analysis revealed the content of the declarations could be broadly categorised into three dimensions: framing, claiming and demanding. The authors demonstrate that these declarations reveal a struggle over the construction of meanings relating to PC and assisted dying and constitute a valuable resource for the analysis of an unfolding debate. **Full text:** <http://bit.ly/2HSjAxg>
- *QUEEN'S LAW JOURNAL* | Online – Accessed 5 February 2019 – ‘**MAiD in Canada?: Debating the Constitutionality of Canada’s New Medical Assistance in Dying Law.**’ Different conceptions of “the good life,” as well as the “the good death,” animate the longstanding and contentious debate surrounding euthanasia and assisted suicide. In *Carter v Canada (Attorney General)*, the Supreme Court of Canada struck down Canada’s blanket prohibition on medical aid in dying (MAiD), but suspended its declaration of invalidity. Parliament responded by amending the Criminal Code to permit MAiD in some circumstances. However, Parliament’s amendment is arguably more restrictive than the vision set out in *Carter*, and has already been the subject of a constitutional challenge. In this context, this article examines *Carter*, the legislative response to *Carter*, and the debates surrounding the new MAiD law, including the challenge to the new law in *Lamb v Canada (Attorney General)*. The author aims to advance understanding of the ways in which interpretations and theories of Canadian constitutional law relate to arguments over the role law can, or should, play in governing MAiD. The author distinguishes three major points of disagreement arising from the debate surrounding the new MAiD law’s constitutionality: the interpretation of the Court’s decision in *Carter*; competing accounts of interpretative authority in constitutional theory; and the role that criminal law should play in governing medical assistance in dying. Examining their relationship, the author seeks to identify broader lessons that can be used when framing debates in Canadian constitutional interpretation. Specifically, the author argues that the debate over *Carter* raises questions not just about how the normative filter function of Canadian constitutional law operates, but also the question of who gets to operate it. While *Carter* may showcase the agency of the courts, equally at issue in the debate over the constitutionality of the new MAiD legislation is the role and authority of Parliament. **Abstract:** <http://bit.ly/2DSkcyU>

N.B. Click on pdf icon to access full text.

- *REVIEW OF RELIGIOUS RESEARCH* | Online – 1 February 2019 – ‘**Witnessing and experiencing miraculous healings and attitudes toward physician-assisted suicide.**’ Drawing on insights from cognitive psychology, the author argues that the religious experiences of witnessing and/or experiencing a miraculous physical healing event will be negatively associated with attitudes towards physician-assisted suicide (PAS). He evaluates this argument using data from the 2007 wave of the Baylor Religion Survey. The author finds that those who have witnessed and/or experienced a miraculous physical healing have more negative attitudes toward PAS than those who have not witnessed and/or experienced such an event, even when controlling for religiosity, socio-demographic, and personality factors. These results show that researchers should consider if and how religious experiences influence people’s attitudes. **Abstract (w. list of references):** <http://bit.ly/2RDRjtS>

Publishing Matters

Updated *Canadian Medical Association Journal* policy on undisclosed competing interests

CANADIAN MEDICAL ASSOCIATION JOURNAL (CMAJ) | Online – 4 February 2019 – Publications in academic journals can have a profound impact on changing practice and supporting policies. However, when authors fail to disclose their competing interests, it can affect a journal's credibility. Such lack of transparency can also undermine public faith in the scientific record, particularly as this problem has been front-page news recently. Notifications about major omissions come at a depressingly regular pace from the watchdog Retraction Watch. Even the perception, rather than the reality, that author conflicts have been obscured can have an impact.¹ The International Committee of Medical Journal Editors (ICMJE) has recently revised its guidance on competing interests¹: deliberate failure to disclose competing interests is academic misconduct, requiring initiation of appropriate procedures,² which may include notification of the author's institution and funders. As a journal that follows ICMJE's recommendations, the *CMAJ* is implementing this guidance. We all have financial and personal interests, academic or institutional affiliations, or political or religious beliefs that may be competing interests.³ A problem arises when these affect our work. For journal editors, for example, competing interests can influence any part of the publication process, from forming an opinion on the design and conduct of a study through to peer review and editorial decision-making. **Full text:** <http://bit.ly/2HVmpOd>



1. 'Recommendations for the conduct, reporting, editing, and publication of scholarly work in medical journals,' International Committee of Medical Journal Editors, December 2018. **Download/view at:** <http://bit.ly/2D71Aey>
2. 'Discussion/guidance document on handling competing interests,' Committee on Publication Ethics, 2016. **Download/view at:** <http://bit.ly/2G842DW>
3. 'Conflict of interest in peer-reviewed medical journals,' World Association of Medical Editors, March 2009. **Download/view at:** <http://bit.ly/2GcDrpc>

Blacklisting or whitelisting? Deterring faculty in developing countries from publishing in substandard journals

JOURNAL OF SCHOLARLY PUBLISHING, 2019;50(2):83-95. A thriving black-market economy of scam scholarly publishing, typically referred to as 'predatory publishing,' threatens the quality of scientific literature globally. The scammers publish research with minimal or no peer review and are motivated by article processing charges and not the advancement of scholarship. Authors involved in this scam are either duped or willingly taking advantage of the low rejection rates and quick publication process. Geographic analysis of the origin of predatory journal articles indicates that they predominantly come from developing countries. Consequently, most universities in developing countries operate blacklists of deceptive journals to deter faculty from submitting to predatory publishers. The present article discusses blacklisting and, conversely, whitelisting of legitimate journals as options of deterrence. Specifically, the article provides a critical evaluation of the two approaches by explaining how they work and comparing their pros and cons to inform a decision about which is the better deterrent. **Full text:** <http://bit.ly/2HXLk3H>

A preliminary study of alternative open access journal indexes

PUBLISHING RESEARCH QUARTERLY | Online – 4 February 2019 – The author examines a group of selected open access journal indexes by non-mainstream index providers. He finds that journals seeking such indexing are mainly "predatory" journals. Most of these so-called alternative indexes have not provided any evidence of employing quality assessment in journal inclusions. They also are not supporting interoperability for online searching across the Web. Comparisons among the alternative indexes yield many overlaps of journals, indicating shared business of these indexes and journals. **Abstract (w. list of references):** <http://bit.ly/2SeVOQM>

Media Watch: Editorial Practice

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ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://bit.ly/2G2jqko>

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CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

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ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

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HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

United States

NEBRASKA | Center for Health Policy & Ethics, Creighton University: <http://bit.ly/2DAED3f>

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