

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.

7 January 2019 Edition | Issue #596



Compilation of Media Watch 2008-2019 ©

Compiled & Annotated by Barry R. Ashpole

'Predatory open-access publishing in palliative and supportive care' (p.13), in *Journal of Pain & Symptom Management*.

Canada

Taquisha McKitty, Brampton woman at centre of brain death court fight, has died, family says

ONTARIO | *The Toronto Star* – 31 December 2018 – A Brampton woman who was at the centre of a legal challenge over the definition of death has died in hospital after having been on life support since September 2017. Taquisha McKitty passed away “peacefully and naturally without the need to pull the plug” ... at Brampton Civic Hospital, said lawyer Hugh Scher, who represents her family in the court battle to keep her on a mechanical ventilator after doctors declared her “dead by neurological criteria” or brain dead and recommended taking her off support. Despite the woman’s untimely death, her family says the case is not moot and hopes the Ontario Court of Appeal will still rule on the appeal it heard earlier in December – and overturn a low-

er court decision in favour of the medical determination of death. The family has argued her Christianity belief recognizes death as when the heart stops beating. <https://goo.gl/T1ZQ1T>

Specialist Publications

'Oncologists communicating with patients about assisted dying' (p.10), in *Current Opinion in Supportive & Palliative Care*.

'Medical assistance in dying: A scoping review to inform nurses' practice' (p.11), in *Journal of Hospice & Palliative Nursing*.

Noted in Media Watch 17 December 2018 (#594, p.1):

- ONTARIO | *The Globe & Mail* (Toronto) – 12 December 2018 – **'Ontario family's legal fight to keep daughter on life support could change how death is defined across Canada.'** Ontario has no statutory definition of death; nor do most Canadian provinces and territories. The determination is instead left up to physicians. Doctors use one of two sets of criteria to declare a patient dead: either a stopped heart or a deceased brain. Some Christians, Muslims, Orthodox Jews and members of other religions feel that “brain death” doesn't align with their definition of life's end, especially if technology can preserve tissue, send swells of air into lungs and keep a heart beating. <https://goo.gl/vNtk8P>

N.B. Selected articles on the ethical and legal aspects of determination of brain death noted in this issue of Media Watch.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- ALBERTA | *The Edmonton Journal* – 29 December 2018 – **‘It’s time to end forced transfers of dying Albertans.’** Because medical assistance in dying (MAiD) is an insured medical service under the province’s public health-care plan, Albertans have a right to equitable access to this important treatment option in accordance with the Canada Health Act and the Canadian Charter of Rights & Freedoms. While the right to MAiD is rooted in fact, claims that public health-care facilities have a right to ban the provision of MAiD are not. Organizations that oppose MAiD, such as Alberta’s Covenant Health, are correct in asserting that staff members who have moral or religious objections to MAiD should not be forced to provide it. Individual clinicians have that right. Bricks-and-mortar institutions – ones that receive substantial public funding and that have a mandate to provide public healthcare to the communities they serve – do not, regardless of whether they have a religious identity. Public outcry over forced transfers has led Covenant Health to relax its MAiD policies slightly. Despite the changes to Covenant’s policy, suffering Albertans will still be forced to move, sometimes to a facility many kilometres outside their home community, to realize their right to a peaceful death. This raises a poignant but necessary question: how many more bereaved families will have to bare their pain in the media, or go to court, for the province to treat people who request MAiD with the compassion and respect they deserve? <https://goo.gl/rDLJqr>

N.B. ‘Medical assistance in dying,’ Government of Canada, modified 12 December 2018. **Download/view at:** <https://goo.gl/F9DChv>

U.S.A.

Schools fall short when it comes to helping students in grief – here’s how they can improve

THE CONVERSATION | Online – 4 January 2019 – An adolescent experiences the death of his mother after a lengthy illness. When I ask what services he would like to receive from the school, he initially says he didn’t expect special treatment, would be embarrassed by counseling from the school mental health staff and wouldn’t feel comfortable if many of his teachers asked to talk to him about his grief. At the same time, the student felt as though the school should somehow take his situation into account. “I don’t know what the school should do,” the student told me. “But I just lost the person I love most in my life and they act as if nothing happened.” In my many years as a developmental-behavioral pediatrician who specializes in school crisis and child bereavement, I believe this dilemma – that is, the need to do enough but not to overwhelm the grieving student or the adults who are trying to help – represents a major challenge for America’s schools. The need for recognition by trusted adults of their loss, a genuine expression of sympathy and an offer of assistance is often what students seek after a major loss – but too often don’t receive. <https://goo.gl/sdsZkJ>

CANADIAN  Portail CANADIEN EN SOINS
Virtual Hospice **palliatifs**

Supporting Grieving or Bereaved Children
<http://goo.gl/ydHfq9>

Specialist Publications

‘Healthcare for undocumented immigrants’ (p.4), in *AMA Journal of Ethics*.

‘Teaching healthcare providers to query patients with cancer about sexual and gender minority status and sexual health’ (p.4), in *American Journal of Hospice & Palliative Medicine*.

‘Commonwealth v. Carter and legal interpretations of facilitated suicide’ (p.11), in *Journal of the American Academy of Psychiatry and the Law*.

American Academy of Neurology calls for uniformity of brain death determination

AMERICAN ACADEMY OF NEUROLOGY | Online – 2 January 2019 – The academy is calling for uniform brain death laws, policies and practices in a new position statement... The position statement is endorsed by the American Neurological Association and the Child Neurology Society. Brain death is defined as the death of the individual due to irreversible loss of function of the entire brain. It is the equivalent of circulatory death, which is due to irreversible loss of function of the circulatory system, which includes the heart. The brain death standards for adults and children that are widely accepted by the medical profession are the following guidelines: the American Academy of Neurology's 2010 'Evidence-Based Guideline Update: Determining Brain Death in Adults'; and, the 2011 'Guidelines for the Determination of Brain Death in Infants and Children,' published by the Pediatric Section of the Society of Critical Care Medicine, the Sections of Neurology & Critical Care of the American Academy of Pediatrics and the Child Neurology Society. The American Academy of Neurology is not aware of any cases in which following these guidelines led to inaccurate determination of death with return of any brain function, including consciousness, brainstem reflexes or breathing. Yet only the state of Nevada has adopted legislation that requires using these widely accepted brain death guidelines as the medical standard, as authorized by the Uniform Determination of Death Act, for the determination of brain death. <https://goo.gl/PirNYD>

1. 'Brain death, the determination of brain death, and member guidance for brain death accommodation requests,' *Neurology*, published online 2 January 2019. **Access options at:** <https://goo.gl/m5iShS>

Noted in Media Watch 31 December 2018 (#595, p.14):

- *THE HASTINGS REPORT*, 2018;48(S4):S2-S5. '**Brain death at fifty: Exploring consensus, controversy, and contexts.**' This special report is published in commemoration of the fiftieth anniversary of the 'Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death,' a landmark document that proposed a new way to define death, with implications that advanced the field of organ transplantation. This remarkable success notwithstanding, the concept has raised lasting questions about what it means to be dead. **Abstract:** <https://goo.gl/7z41oz>

N.B. Additional articles on defining "brain death" noted in 17 December 2018 issue of Media Watch (#594, pp.1-2).

DC pledged to end homelessness by 2020, yet 54 people died without a home this year

WASHINGTON DC | Greater Washington – 2 January 2019 – Advocates, faith leaders, and community members gathered for the annual Homeless Memorial Vigil to remember the 54 people who died without the dignity of a home in DC in 2018. Those who died ranged in age from 25 to 87, with the median age being 57. The average life expectancy in DC is 76.8, illustrating the toll that DC's lack of universal housing takes on the lowest-income members of our community. Not only did 54 people die on DC's streets, an additional 83 members of the homeless community died in 2018 after moving into housing, some from health conditions that likely would have been diagnosed and treated earlier had they had access to housing and healthcare. <https://goo.gl/uFyn4t>

N.B. Selected articles on palliative and end-of-life care for the homeless in the U.S. noted in 1 October 2018 issue of Media Watch (#583, p.3).

Changing how we die: Hospice care surges in Minnesota

MINNESOTA | *Pioneer Press* (St. Paul) – 30 December 2018 – The remarkable rise of hospice care has been powered by grassroots promotions – books, plays and radio programs to review the various pathways to the grave. "Death Cafes" in public places are proliferating, as forums for topics that were once taboo. Doctors, the gatekeepers of hospice entries, now accept hospice as a natural alternative to their expensive and often uncomfortable treatments. Minnesota's hospice population spiked to 19,253 in 2016, the latest year for which statistics are available. This includes people getting care in their homes, as well as those living in hospice centers. One reason for the surge is the aging of America. But the increase in the number of people over 65 since 2000 – 35% – isn't enough to explain the tripling of hospice use. The main reason ... is that doctors have stopped fighting or ignoring hospices. <https://goo.gl/nLQc88>

Specialist Publications

Healthcare for undocumented immigrants

AMA JOURNAL OF ETHICS, 2019;21(1). Currently, 800,000 Deferred Action for Childhood Arrivals (DACA) recipients [in the U.S.] – including many health professionals, students, and patients – face risk of detention and deportation. Loss of DACA status could relegate many of these young people to a life marked by fear and uncertainty. This issue of the journal considers the nature and scope of clinicians' obligations to support and care for undocumented immigrants, refugees, and asylees. **Journal contents page:** <https://goo.gl/1kK1r7>

Noted in Media Watch 21 May 2018 (#564, p.2):

- *KAISER HEALTH NEWS* | Online – 18 May 2018 – **'Choosing between death and deportation.'** What happens when an undocumented immigrant has a life-threatening diagnosis? Much depends on where they live. And, even in states with generous care for a dire illness, a patient can face difficult life-and-death choices. <https://goo.gl/NvSYN4>

N.B. Additional articles on undocumented immigrants in the U.S., in the context of palliative and end-of-life care, noted in 5 March 2018 issue of Media Watch (#553, p.10).

Teaching healthcare providers to query patients with cancer about sexual and gender minority status and sexual health

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 1 January 2019 – End of life (EoL) is difficult for all patients but sexual and gender minorities (SGM) are prone to isolation and loneliness, especially if their SGM status is unknown or unaccepted. In oncology clinics, where goals of care discussions about EoL are integral and frequent, querying patients about their SGM status and sexual health is of particular importance. The American Society of Clinical Oncology recently released a position statement that called for greater focus on SGM populations with the goal of reducing and eventually eliminating disparities in cancer care within this group.¹ An important first step in addressing such disparities is learning how best to train cancer healthcare providers to ask patients about their SGM status and about sexual health in general. This article summarizes the mandate for understanding cancer issues in SGM populations and the dearth of cancer-related data within this group. This article also describes an ongoing 3-part study intended to build a mini curriculum with the goal of helping cancer healthcare providers to ask patients with cancer about SGM status and to ask all patients with cancer about sexual health issues. The results of this ongoing study could potentially improve EoL care for sub-groups of patients. **Abstract:** <https://goo.gl/Uc3FsW>

1. 'Reducing disparities in cancer care for sexual and gender minority individuals,' Policy Issue Brief, American Society of Clinical Oncology, May 2018. **Download/view at:** <https://goo.gl/JsXyN8>

Publishing Matters

'Correcting duplicate publications: Follow up study of MEDLINE tagged duplications' (p.11), in *Biochemia Medica*.

'Amateurism still flourishing in scientific journals' (p.12), in *The BMJ Opinion*.

'Predatory publications in evidence syntheses' (p.12), in *Journal of the Medical Library Association*.

'Predatory open-access publishing in palliative and supportive care' (p.13), in *Journal of Pain & Symptom Management*.

'An approach to conference selection and evaluation: Advice to avoid "predatory" conferences' (p.13), in *Scientometrics*.

Cont.

Noted in Media Watch 1 January 2018 (#544, p.20):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 27 December 2017 – ‘**Current best practices for sexual and gender minorities in hospice and palliative care settings.**’ Although several publications document the healthcare disparities experienced by sexual and gender minorities (SGMs), including lesbian, gay, bisexual, and transgender (LGBT) individuals, less is known about the experiences and outcomes for SGM families and individuals in hospice and palliative care (HPC) settings. This article provides a brief overview of issues pertaining to SGMs in HPC settings, highlighting gaps in knowledge and research. Current and best practices for SGM individuals and their families in HPC settings are described, as are recommendations for improving the quality of such care. **Abstract:** <https://goo.gl/P8dsWG>

Visualizing end-of-life care

Caring for dying patients: Visual narratives from the intensive care unit

ANNALS OF INTERNAL MEDICINE | Online – 1 January 2019 – *I started this series of drawings from my desire to illustrate my experiences as a medical student in treating intensive care patients through art. Although I felt comfortable discussing all aspects of my patients' clinical care, I struggled to verbalize the unspoken ethical dilemmas permeating through every patient interaction. These thoughts lingered in my head for months until I decided to express them through color, line, and form. Creating these visual images helped me to reflect and better understand how our daily medical interventions truly impact patient care. For viewers, I hope these images facilitate more mindful ways to care for patients and their families as they face illness and death. Each drawing represents a composite of patients I have encountered, and I used donated cadavers from the New York University Anatomy Lab to help accurately depict the anatomy in my illustrations. Full (illustrated) text:* <https://goo.gl/1zpw6>

What patients, families, health professionals and hospital volunteers told us about advance directives

ASIA PACIFIC JOURNAL OF ONCOLOGY NURSING, 2019;6(1):

72-77. The findings of this study reveal the influence of Chinese culture on advance directives (AD). As the concept of filial piety is important to Chinese, the family factor cannot be ignored. Some patients in the study stressed their responsibility to take care of their families. Other studies found that patients did not want to be a burden on their family. The opinion of the family has a great impact on decisions and outcomes concerned with the AD. A study on dialysis patients found that the majority had discussed their preferences with their family before completing AD. Those who did not sign an AD believed their family knew what they would want. However, the study also reported some family members might change their minds after patients had signed AD. Family disagreement with AD decisions poses a significant problem for the execution of AD. Health professionals may assess the cognitive ability and mental status of patients to ensure they understand the purpose and content of AD, and that their decisions will not be affected by distress – thus making them ready for AD discussion. As Chinese people tend to avoid discussing death, it is preferable if the physician-initiates discussion. Studies from Western countries have also found that asking individuals to complete AD can increase the completion rate. Health professionals can help patients to recall their feelings about what they have experienced and observed during hospitalization to facilitate their decision-making. The discussion process is important to involve patients, family and health professionals in understanding patients' views and reducing any conflict over making decisions that might hinder the execution of AD. **Full text:** <https://goo.gl/KudeJZ>



香港中文大學
The Chinese University of Hong Kong



Share this issue of Media Watch with a colleague

What does the word “treatable” mean? Implications for communication and decision-making in critical illness

CRITICAL CARE MEDICINE | Online – 21 December 2018 – The authors identified two distinct concepts that study participants used to interpret the word “treatable”: 1) A “good news” concept, in which the word “treatable” conveys a positive message about a patient’s future, thereby inspiring hope and encouraging further treatment; and, 2) An “action-oriented” concept, in which the word “treatable” conveys that physicians have an action or intervention available, but does not necessarily imply an improved prognosis or quality of life. The overwhelming majority of non-physicians adopted the “good news” concept, whereas physicians almost exclusively adopted the “action-oriented” concept. For some non-physicians, the word “treatable” conveyed a positive message about prognosis and/or further treatment, even when this contradicted previously stated negative information. Physician use of the word “treatable” may lead patients or surrogates to derive unwarranted good news and false encouragement to pursue treatment, even when physicians have explicitly stated information to the contrary. Further work is needed to determine the extent to which the word “treatable” and its cognates contribute to widespread decision-making and communication challenges in critical care, including discordance about prognosis, misconceptions that palliative treatments are curative, and disputes about potentially inappropriate or futile treatment. **Abstract:** <https://goo.gl/qvdtZD>

Place of death and associated factors: A population-based study using death certificate data

EUROPEAN JOURNAL OF PUBLIC HEALTH | Online – 2 January 2019 – Although studies suggest that most people prefer to die at home, not enough is known about place of death patterns by cause of death considering socio-demographic factors. All death certificate data on the residents in Spain aged 15 or over who died in Spain between 2012 and 2015 were included. Over half of all deaths occurred in hospital (57.4%), representing double the frequency of deaths that occurred at home. All the socio-demographic variables (sex, educational level, urbanization level, marital status, age and country of birth) were associated with place of death, although age presented the strongest association. Cause of death was the main predictor with heart disease, neurodegenerative disease, Alzheimer’s disease, dementia and senility accounting for the highest percentages of home deaths. Cause of death presented a stronger association with place of death than socio-demographic variables; of these latter, age, urbanization level and marital status were the main predictors. These results will prove useful in planning end-of-life care that is more closely tailored to people’s circumstances and needs. **Abstract:** <https://goo.gl/8rsnFf>

The shady pink elephant: End-of-life education for young women affected by breast cancer

JOURNAL OF CANCER EDUCATION | Online – 27 December 2018 – The main objective of this study was to evaluate the impact of the Young Survival Coalition end-of-life (EoL) educational series on participants’ knowledge, beliefs and behaviors regarding understanding and accessing palliative care (PC) as well as deciding upon and communicating EoL wishes. While all knowledge, beliefs and behaviors on EoL scores tended to improve from baseline to 6-month post survey, not all were statistically significant. Participants were significantly more likely to discuss their EoL wishes with co-survivors 6 months after the intervention. They also reported a significantly better understanding of the individual parts of an advance directive 6 months after the intervention. Beliefs about PC and the importance of having early EoL discussions also significantly improved 6 months after the intervention. Comfort levels around talking about EoL issues also significantly improved 6 months after the intervention. Participants’ confidence that their wishes would be honored by their healthcare power of attorney significantly improved at 6-month post intervention, as well as their reported knowledge of the important characteristics of these assigned agents. **Full text:** <https://goo.gl/BVSauR>

N.B. Additional articles on PC for patients living with breast cancer noted in 10 December 2018 issue of Media Watch (#593, p.9).

Compassion fatigue in palliative care nursing: A concept analysis

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(1):21-28. Compassion fatigue was first introduced as a description for nursing burnout; however, it was not fully described. An initial concept analysis within nursing placed it in terms of a psychological model for secondary traumatic stress disorder, with continual revisions of this application. Palliative care (PC) nurses are routinely exposed to pain, trauma, and the suffering they witness by nature of ongoing symptom management and end-of-life (EoL) care delivery; however, the focus of care is on healthy EoL management rather than preservation of life. The literature was reviewed to provide clarification of compassion fatigue for PC nurses to assist in future identification and direction in the profession. Identification of compassion fatigue for this profession helps facilitate the recognition of symptoms for a group that deals with patient suffering on a regular basis. **Full text:** <https://goo.gl/LmKt4r>

Patients' autonomy at the end of life: A critical review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 3 January 2019 – The predominating definition of autonomy as a capacity to make an independent rational choice may not be suitable for patients in palliative care. Therefrom arises the actual need for more contextualized perspectives on autonomy to promote the quality of life and satisfaction with care of terminally ill patients. Of the 5540 articles surveyed, 19 qualitative and 8 quantitative studies met the inclusion criteria. The authors identified two core structural domains of autonomy: 1) Being normal; and, 2) Taking charge. By analysing these domains they described 8 and 13 elements, respectively, which map the conceptual structure of autonomy within this population of patients. The review shows that maintaining autonomy at the end of life is not only a concern of making choices and decisions about treatment and care but that emphasis should be also put on supporting the patients' engagement in daily activities, in contributing to others, and in active preparation for dying. **Abstract (inc. link to references):** <https://goo.gl/aEXdDv>



A life or “good death” situation? A worldwide ecological study of the national contexts of countries which have and have not implemented palliative care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 December 2018 – Palliative Care (PC) advocates argue that service implementation is feasible in all settings. Yet, services have developed patchily in low and middle-income settings. Beyond Human Development Index indicators, there has been limited engagement with the broader development challenges facing nations tasked with implementing PC. Twenty-six out of 28 variables were statistically significantly associated with levels of PC development in 207 countries. PC is more developed in countries with high: percentage of deaths from non-communicable disease; population proportion aged 65+; and, gross national income and tourism. Development is lower in countries with high levels of: political corruption; infant mortality; deaths by infectious diseases; and, weak democracy. Prevalence of under-nourishment and levels of private health expenditure were not significantly associated with PC development. PC development is highly consistent with broader national development indicators. It is less in countries where sudden deaths are more likely and benefits from PC provision are likely to be very limited. In such countries, resources may be prioritised towards life-prolonging therapies and key aspects of PC need only be implemented prior to fully integrated palliative services. Findings suggest that there may be a ‘tipping point’ in societies, where the relative need for life-prolonging therapies becomes less than the need for integrated PC services. **Abstract (inc. link to references):** <https://goo.gl/kDfUDq>

Attitudes of the general public, cancer patients, family caregivers, and physicians toward advance care planning: A nationwide survey prior to the enforcement of the life-sustaining treatment decision-making act

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 26 December 2018 – To respect a patient’s wish for end-of-life care, the ‘Act on [Hospice & Palliative Care and] Decisions on Life-



Sustaining Treatment for Patients at the End-of-Life’ was enacted in South Korea in 2016. A total of 15% of the general population, 33% of the patients and caregivers, and 61% of the physicians had knowledge of advance directives. More than 64% of the general population, above 72% of the patients and caregivers, and 97% of the physicians were willing to do so [*sic*] when the disease status was aggravated or terminal. The possibility for changing the plan, uncertainty as to whether directives would actually be followed, and psychological discomfort were common reasons for not wanting to engage in advance care planning (ACP). Routine recommendations for a specific medical condition, heightened accessibility, and health insurance support were common factors that could help facilitate ACP. The authors’ findings suggest that strategies for promoting ACP should reflect different perspectives among the general public, patients, family caregivers, and physicians. Public advocacy, resources for approaching and integrating ACP into routine healthcare, as well as systematic support provisions, are needed. **Abstract (inc. link to references):** <https://goo.gl/iSfp1Z>

Noted in Media Watch 31 December 2017 (#595, p.6):

- SOUTH KOREA | *The Korea Times* (Seoul)– 30 December 2018 – ‘**Organization launched for “well-dying.”**’ In an aged society ... what becomes important is how to live in later life and how to end life with dignity. In this context, civic group members, lawmakers, scholars and businesspeople have formed a group for “well-dying.” The group is aimed at helping individuals prepare better for their later years and a beautiful ending to their lives in a super-aged society, where the elderly aged 65 or over take up over 20% of the total population. The group will concentrate on teaching patients how to write an advance medical directive. <https://goo.gl/5Zyddi>

Noted in Media Watch 3 December 2018 (#592, p.7):

- SOUTH KOREA | *The Korea Times* (Seoul) – 25 November 2018 – ‘**Rule on ending life-sustaining treatment to be more practical.**’ The regulation on ending life-sustaining treatment for terminally ill patients will be eased next year to become more practical, narrowing the scope of “family consent” required for approval of the cessation. According to the Ministry of Health & Welfare, the National Assembly recently passed the revision to the law to allow patients to end medical treatment after getting consent from their spouse, parents and children only. The new regulation will take effect on March 28 next year. <https://goo.gl/7RCQv3>

Noted in Media Watch 15 October 2018 (#585, p.6):

- SOUTH KOREA | *The Chosunilbo* (Seoul) – 10 October 2018 – ‘**Over 20,000 refuse life-prolonging treatment since law change.**’ More than 20,000 Koreans have chosen to refuse life-prolonging treatment since the law changed to permit living wills to that effect earlier this year after a three-month trial run. The Ministry of Health & Welfare reports that 20,742 people opted to discontinue life support treatment from February until last Wednesday [3 October 2018]. One out of three patients gave doctors permission to discontinue life support when their illnesses became terminal, and the families of two out of three terminally ill patients chose death with dignity for their loved ones. <https://goo.gl/M22M8S>

Comparing the costs of alternative models of end-of-life care

JOURNAL OF PALLIATIVE CARE | Online – Accessed 3 January 2019 – This study explores the financial consequences of decreased acute care utilization and expanded community-based care for patients at the end of life in England. The authors estimated at £1.8 billion the cost to the taxpayer of care for the 127,000 patients dying from cancer in 2006. The equivalent cost for the 30,000 people dying from organ

Cont.

failure was £553 million. Resources of £16 to £171 million could be released for cancer. People generally prefer to die outside hospital. The results of this study suggests that reducing reliance on acute care could release resources and better meet peoples' preferences. Better data on the cost-effectiveness of interventions are required. Similar models would be useful to decision-makers evaluating changes in service provision. **Abstract:** <https://goo.gl/oSKzcC>

Planning ahead with dementia: What role can advance care planning play? A review on opportunities and challenges

SWISS MEDICAL WEEKLY | Online – 30 December 2018 – Advance directives (ADs) emerged in the 1960s with the goal of empowering people to exert control over their future medical decisions. However, it has become apparent, over recent years, that ADs do not sufficiently capture the temporal and relational aspects of planning treatment and care. Advance care planning (ACP) has been suggested as a way to emphasise communication between the patient, their surrogate decision maker and healthcare professional(s) in order to anticipate healthcare decisions in the event that the patient loses decision-making capacity, either temporarily or permanently. In more and more countries, ACP has become common practice in planning the treatment of terminal diseases such as cancer or amyotrophic lateral sclerosis. However, even though neurodegenerative dementia results in the gradual loss of decision-making capacity, ACP is still extremely rare. There are several reasons for this. Firstly, some people have difficulties talking about illness and death, especially when this involves anticipation. Secondly, lay people and professionals alike struggle to consider Alzheimer's disease and similar forms of dementia as terminal diseases. Thirdly, although patient decision-making capacity grad-

ually decreases with the progression of dementia, the patient retains the ability to communicate and interact with surrogates and professionals until the later stages of the disease. Therefore, surrogates and professionals may feel unsure or even ambivalent when enforcing ADs, in particular when those decisions may shorten a patient's life expectancy. Finally, to be effective, existing ACP interventions should be adapted to patient's cognitive impairments and lay out dementia-specific scenarios. The aim of this article is to identify the benefits and challenges of ACP in dementia care, outline strategies to design appropriate procedures and tools, and provide professionals, patients and their relatives with opportunities to engage in ACP. **Full text:** <https://goo.gl/41xPFg>

European Association for Palliative Care

Advance Care Planning and Advance Directives: A clear and concise expression of the patient's wishes regarding personal care and medical treatment or therapeutic interventions. **Blog:** <https://goo.gl/SyTuQ7>

Cont. next page



[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>



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

Noted in Media Watch 31 December 2018 (#595, p.16):

- *AMERICAN JOURNAL OF ALZHEIMER'S DISEASE & OTHER DEMENTIAS* | Online – 13 December 2018 – ‘**Empowering patients with Alzheimer’s disease to void unwanted medical care: A look at the dementia care triad.**’ The authors examine the role of each member of the dementia care triad and how to empower the patient to participate in planning future medical care. Physicians have the same professional disclosure obligations to dementia patients as they do to all other capable patients with terminal illnesses. Because there is little consensus about what facts should be included in a diagnostic disclosure, the authors offer a proposal to empower newly diagnosed patients with dementia with capacity to plan for their future medical care. **Abstract:** <https://goo.gl/Kgr33S>

Noted in Media Watch 12 November 2018 (#589, p.13):

- *PALLIATIVE MEDICINE* | Online – 8 November 2018 – ‘**Perspectives of people with dementia and carers on advance care planning and end-of-life care: A systematic review and thematic synthesis of qualitative studies.**’ Five themes were identified: 1) Avoiding dehumanising treatment and care (remaining connected, delaying institutionalisation, rejecting the burdens of futile treatment); 2) Confronting emotionally difficult conversations (signifying death, unpreparedness to face impending cognitive decline, locked into a pathway); 3) Navigating existential tensions (accepting inevitable incapacity and death, fear of being responsible for cause of death, alleviating decisional responsibility); 4) Defining personal autonomy (struggling with unknown preferences, depending on carer advocacy, justifying treatments for health deteriorations); and, 5) Lacking confidence in healthcare settings (distrusting clinicians’ mastery and knowledge, making uninformed choices, deprived of hospice access and support at end of life). **Full text:** <https://goo.gl/8QDxL2>

Palliative care for acute kidney injury patients in the intensive care unit

WORLD JOURNAL OF NEPHROLOGY, 2018;7(8):148-154. Patients with acute kidney injury (AKI) in the intensive care unit (ICU) are often suitable for palliative care (PC) due to the high symptom burden. The role of palliative medicine in this patient population is not well defined and there is a lack of established guidelines to address this issue. Because of this, patients in the ICU with AKI deprived of the most comprehensive or appropriate care. The reasons for this are multifactorial including lack of PC training among nephrologists. However, PC in these patients can help alleviate symptoms, improve quality of life, and decrease suffering. PC physicians can determine the appropriateness and model of PC. In addition to shared decision-making, advance directives should be established with patients early on, with specific instructions regarding dialysis, and those advance directives should be respected. **Full text (via PubMed):** <https://goo.gl/2iR9ke>

N.B. Selected articles on palliative and end-of-life care for people living with chronic kidney disease noted in 13 August 2018 issue of Media Watch (#576, p.15).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE* | Online – 2 January 2019 – ‘**Oncologists communicating with patients about assisted dying.**’ Across all jurisdictions in which assisted dying is legally permissible, cancer is the primary reported underlying diagnosis. Therefore, oncologists are likely to be asked about assisted dying and should be equipped to respond to inquiries or requests for assisted dying. Because medical assistance in dying was legalized in Canada in 2016, it is a relatively new end-of-life practice and has prompted the need to revisit the academic literature to inform communication with patients about assisted dying. The authors reviewed applicable literature published in the past 5 years, pertaining to assisted dying and communication. In total, 86 articles were identified, 21 were flagged as relevant to review in detail, and six were included in the review. Key themes included perceived barriers and benefits to communicating with patients on the topic, pragmatic approaches for facilitating the conversation with patients, and the issue of proactively discussing assisted dying by broaching it as an option with patients. **Abstract:** <https://goo.gl/4HsXGi>

Cont.

- *JOURNAL OF THE AMERICAN ACADEMY OF PSYCHIATRY AND THE LAW*, 2018;46(4):521-531. '**Commonwealth v. Carter and legal interpretations of facilitated suicide.**' In June 2017, a media frenzy ensued after Michelle Carter was convicted of involuntary manslaughter in the state of Massachusetts for facilitating the suicide of Conrad Roy. The verdict stirred controversy and cast a spotlight on facilitation of suicide, i.e., a person's act(s) done with the purpose of helping another to die by suicide. One form of facilitation, physician-assisted suicide, has been extensively debated in the existing literature. In this article, the authors set out to explore the legal and forensic ramifications of non-physician-assisted suicide, which they refer to as facilitated suicide. They first conducted a review of all fifty states' legislation regarding facilitated suicide: forty-four states prohibit it by statute, and three states prohibit it through common law. Thirteen states specifically outlaw verbal facilitation of suicide. The authors then surveyed the case law to identify legal precedent to the *Commonwealth v. Carter* verdict. *Final Exit Network, Inc. v. State* and *State v. Melchert-Dinkel* provide contrasting yet complementary perspectives on the interplay between speech and assisted suicide. Finally, they detail the role of forensic psychiatry in investigating facilitated suicide, specifically among adolescents and youths. **Full text:** <https://goo.gl/epEJE2>
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2019;21(1):46-53. '**Medical assistance in dying: A scoping review to inform nurses' practice.**' In June 2016, Bill C-14 or Medical Assistance in Dying (MAiD) legislation became law in Canada. With this law came changes to nurses' (i.e., nurse practitioner, registered nurse, registered practical nurse) scopes of practice, roles, and responsibilities. While federal law, regulatory, and organizational policies are developed to inform nurses about the practice of MAiD, there is little evidence examining how nurses' roles and responsibilities are enacted in practice. Therefore, a scoping review was conducted to synthesize the evidence on nurses' roles and responsibilities in relation to MAiD and to identify gaps in the literature. A secondary aim was to identify organizational supports for nurses to effectively and ethically engage in MAiD. The findings from 24 research studies were synthesized in this article. The analysis highlights the importance of effective health care professional engagement with the individual in the decision-making process and of the need to educate, support, and include nurses in providing medical assistance in dying. Overall, the current research on MAiD is limited in Canada, and more attention is needed on the role of the nurse. **Abstract:** <https://goo.gl/LP3HcS>

Publishing Matters

Correcting duplicate publications: Follow up study of MEDLINE tagged duplications

BIOCHEMIA MEDICA | Online – Accessed 2 January 2019 – Duplicate publication (DP) is a publication that substantially overlaps with one already published, but does not appropriately acknowledge its source. This practice can inflate an author's or journal's prestige, but wastes time and resources of readers, peer reviewers, and publishers. Duplication of data can also lead to biased estimates of efficacy or safety of treatments and products in meta-analyses of health interventions, as the same data which is calculated twice exaggerates the accuracy of the analysis, and leaves an impression that more patients were involved in testing a drug. Not referencing the origin or the overlap of the data, can therefore be considered akin to fabrication, as it implies the data or information is new, when in fact it is not. For these reasons, all major international editorial organizations, including the Committee on Publication Ethics, the Council of Science Editors, and the International Committee of Medical Journal Editors, recommend retracting DPs. A 2014 study of MEDLINE retractions showed that duplication accounted for 22% (506 out of 2,343) of retracted publications. Retracted publications in MEDLINE are tagged following the formal issuance of retraction by an authorized party (e.g., author or a journal). Duplicate publications, however, are tagged whenever substantial overlap between two or more articles is discovered during indexing, irrespective of an authorized notification. Furthermore, the DP [Publication Type] tag is given to both the duplicate(s) and to the original article(s). Indexers, however, do not routinely examine articles for originality, so the tagged DPs do not necessarily include all instances of DPs in MEDLINE. **Full text:** <https://goo.gl/XWAapH>



N.B. See 'Journals are failing to address duplication in the literature, says a new study,' an interview with lead author of the *Biochemia Medica* article, Mario Malički, at Retraction Watch: <https://goo.gl/ixVVZf>

Amateurism still flourishing in scientific journals

THE BMJ OPINION | Online – 31 December 2018 – In 1995 Stephen Lock, once editor of the *British Medical Journal*, and effectively the first person in Britain to be seriously concerned about research misconduct, called for an end of amateurism in the editing of scientific journals. He made his plea after reviewing a report on the gross failures of the editors of the *British Journal of Obstetrics & Gynaecology* in publishing two fraudulent papers which had the editor of the journal as an author on one and an assistant editor as an author on both.¹ But more than 20 years later a report in the *Toronto Star* appears to show that amateur editing is flourishing as ever.² The report in the *Toronto Star* describes how a review of more than 1,400 papers by Gideon Koren, one of Canada's most prolific scientific authors, "reveals the inability – and unwillingness – of journals and research institutions to preserve the integrity of the scientific record." Many journals had been notified of problems in the papers by Koren, but most of them had done nothing. The article quotes Ivan Oransky, founder of Retraction Watch, describe "the vaunted self-correction mechanism of science" as one that is "held together by spit and bubble gum." Retraction Watch, which reports almost every day on malfeasance in science, has brought to global prominence what Lock knew a quarter of a century ago – that research misconduct is common, poorly acknowledged, and inadequately managed. **Full text:** <https://goo.gl/Zyriqy>



1. 'Lessons from the Pearce affair: Handling scientific fraud,' *British Medical Journal*, published online 17 June 1995. **Introductory paragraphs:** <https://goo.gl/P9cxov>
2. 'Inside the flawed world of medical publishing that allowed a lie in a paper co-authored by Dr. Gideon Koren to pollute the scientific record,' *The Toronto Star*, 21 December 2018. <https://goo.gl/yT6rbT>

Predatory publications in evidence syntheses

JOURNAL OF THE MEDICAL LIBRARY ASSOCIATION, 2019;107(1): 57-61. The purpose of peer review is to establish and maintain a standard for research in a particular field. This standard not only keeps researchers honest, but also allows readers (or authors of a systematic review) to feel secure that the rigor of the research and interpretation of the findings has been addressed and maintained by the publishing journal and that the article can be considered to make a valuable contribution to the state of knowledge. Given that not all readers are experts in content or methodology, the contribution of a manuscript without the standards provided by peer review is suspect at best. The publisher the authors selected for this examination is allegedly engaged in questionable business practices and is known to have limited, or even nonexistent, peer review. In particular, the publisher has been found in a U.S. federal court injunction to not engage in peer review, to fraudulently misrepresent their impact factor, and to engage in deception by failing to adequately disclose publication fees. For this reason, the authors are concerned to see continued citing of research published in these journals, particularly in research syntheses, without knowing whether the authors of the reviews are aware of this problematic history of the journals. Systematic review authors need to be vigilant for articles published in predatory journals that can appear to be legitimate. Using a checklist or critical appraisal tool to ensure that only papers of high quality are included in a research synthesis will reduce the risk of including poor-quality research and potentially changing outcomes on that basis. This is the case for both poor-quality research published in high-quality journals and poor-quality research published in predatory journals. A plethora of critical appraisal tools are available for evaluating research by employing many different research methodologies. Systematic review publishers such as Cochrane, Campbell, the Evidence for Policy and Practice Information (EPPI), and the Joanna Briggs Institute all recommend the use of critical appraisal tools to evaluate the quality of research cited in a systematic review. **Full text:** <https://goo.gl/JcQ7yA>



Closing the Gap Between Knowledge & Technology
<http://goo.gl/OTpc8l>

Predatory open-access publishing in palliative and supportive care

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 27 December 2018 – Predatory publishing is commonly defined as an exploitative, fraudulent, open-access model that applies charges to authors without providing proper editorial services, characteristic of legitimate journals. This phenomenon is universally considered as one of the most serious threats to scientific community. To enhance awareness among scholars and clinicians, predatory publishing has been surveyed in several biomedical fields, such as neuroscience, orthopedics, rehabilitation, and anesthesiology. **Abstract (inc. link to references):** <https://goo.gl/dAP5jt>

An approach to conference selection and evaluation: Advice to avoid “predatory” conferences

SCIENTOMETRICS | Online – 15 December 2018 – The authors surveyed ... 150 faculty members and medical residents at the University of Calgary requesting them to rank factors, which may be useful in their conference selection. They also evaluated both faculty and resident’s knowledge of and exposure to presumed “predatory” science. The most important factors in selecting a conference(s) for residents is being focused on their area of interest, having an opportunity to present work, having well known respected plenary speakers, networking potential, and being recommended by colleagues. Residents placed more importance on cost, location and time of year of the conference than faculty. Faculty placed more emphasis on networking potential, sponsoring organization, obtaining continuing professional development credits and the likelihood that cutting edge research will be presented. Most faculty (71%) had received correspondence from presumed “predatory” publishers or conferences, however only 56% of residents had ever either heard of or had education about “predatory science.” Experienced faculty need to provide advice and mentorship to trainees on conference value. In the absence of any formal tool for assessing conference quality their proactive guidance remains critical for medical students and residents. There is a significant lack of awareness and education for both trainees and some faculty around “predatory” publications and conferencing making them particularly vulnerable to misusing time and resources. Improved knowledge, education and new metrics are required to safeguard the academic community in this new era of “predatory academia.” **Abstract:** <https://goo.gl/1XhrLi>

Noted in Media Watch 19 March 2018 (#555, p.15):

- *UNIVERSITY AFFAIRS* | Online – 5 March 2018 – ‘**Poor quality, predatory conferences prey on academics.**’ Many publishers of deceptive or poor-quality academic journals have created a big sideline business organizing equally questionable academic conferences. Yet some professors don’t seem to be getting the message to stay away. McGill University professor Eduardo Franco discovered last year, to his dismay, that OMICS International, one of these publishers, listed 220 McGill professors whom the company claimed had served as “editors, contributors and speakers” for OMICS journals and conferences. **Full text:** <https://goo.gl/h5G9ed>

N.B. OMICS publications include the *Journal of Palliative Care & Medicine*: <http://goo.gl/ieTbLZ>. In November 2017, a U.S. federal court granted a preliminary injunction against OMICS requested by the Federal Trade Commission “temporarily halting the deceptive practices” of the publisher.

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.

Cont.

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](http://goo.gl/frPgZ5)

Media Watch: Access on Online

Updated 01.04.2019

International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/S34vvs>

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

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

PALLIMED: <http://goo.gl/7mrqMQ>

[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']

Canada



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/IOSNC7>

Cont.

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <https://goo.gl/SyTuQ7>

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>

United States

NEBRASKA | Center for Health Policy & Ethics, Creighton University: <https://goo.gl/JVEprv>

[Scroll down to 'Barry Ashpole's Media Watch']

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net