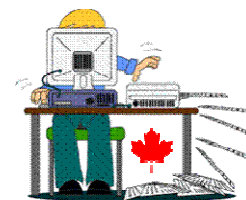


## Media Watch...

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

**Policy initiatives to promote shared decision making (SDM) implementation in clinical practice carry the risk of several unintended negative consequences if limitations in defining and measuring SDM are not addressed.**

'Potential unintended consequences of recent shared decision making policy initiatives' (p.8), in *Health Affairs*.

## Canada

### **Dying with dignity: The growing importance of palliative care in Canada**

*MCGILL JOURNAL OF LAW & HEALTH* | Online – 5 November 2019 – One contributing factor to the limited accessibility of palliative care (PC) is that it is mostly delivered in hospitals. As a result, most Canadians living with life-limiting illnesses die in hospitals, despite their wishes to die at home. This mode of delivery limits the accessibility of PC in remote areas, where there are fewer hospitals. Also, those who fear hospitals may be hesitant to access PC. This fear may be more prevalent in Indigenous communities, due to a long history of violence and oppression from the days of the Indian hospitals, which forcibly hospitalized Indigenous peoples suffering from communicable diseases and subjected them to horrific treatment and conditions. Although the last of the Indian hospitals closed in 1981, the fear of hospitals lives on in Indigenous communities. To this day, many Indigenous peoples continue to experience racism and receive culturally insensitive care in hospitals, which only serves to perpetuate their deep-seated mistrust of the healthcare system. As a result, most Indigenous peoples only access PC once their disease has progressed to its final

stages. A growing body of evidence suggests that there are greater benefits, such as reduced physical and psychological distress for the patients and their families, when PC is delivered at the onset of the disease. Early access to PC not only benefits the patient and their families but also reduces hospitalization costs that result from the continual treatment of a disease. This is especially important for Indigenous peoples, who suffer from higher instances of chronic illnesses, such as diabetes, cancer, cardiovascular and infectious diseases, as compared to other Canadians. <http://bit.ly/2CojSGI>

### Specialist Publications

'**Conscientious objection to medical assistance in dying: A qualitative study with Quebec physicians**' (p.14), in *Canadian Journal of Bioethics*.

'**Medical assistance in dying: A point-of-care educational framework for attending physicians**' (p.14), in *Teaching & Learning in Medicine*.

Cont.

## Related

- ONTARIO | *Anishinabek News* (Thunder Bay) – 5 November 2019 – **‘Framework for Anishinabek approach to palliative care developed for North Shore Tribal Council communities.’** The development of a culturally safe palliative care (PC) model for the North Shore Tribal Council communities, ‘Innovative or Reclaiming our Anishinabek Approach to Palliative Care,’ was the subject at a recent conference. The catalyst to develop the PC model was the experience that Indigenous families were having with their loved ones who had passed in hospital. Families wanted to bring their loved ones home and to care for them there. Currently, communities do not have funding for the model. <http://bit.ly/2NSw7kb>

**N.B.** Selected articles on access to PC in Canada and on end-of-life care for Indigenous peoples of Canada noted in 4 November 2019 issue of *Media Watch* (#628, pp.1-2, and p.12, respectively).

## U.S.A.

### Judge blocks federal “conscience rule” from going into effect

*MCKNIGHT'S SENIOR LIVING* | Online – 7 November 2019 – A judge ... blocked a federal rule that would have allowed individual healthcare workers as well as healthcare organizations to decline to provide care that conflicted with their religious and moral beliefs or mission. The “conscience rule” had been set to go into effect 22 November. U.S. District Judge Paul A. Engelmayer ... vacated the rule entirely, saying it was unconstitutional. The Department of Health & Human Services (H&HS), he said, exceeded its authority and “acted arbitrarily and capriciously” in publishing it. The department’s violations of federal law were “numerous, fundamental and far-reaching,” Engelmayer wrote. The rule, the judge said, would have imposed “ambiguous and retroactive conditions” on the states and would have been “impermissibly coercive” given that the government potentially could have withheld hundreds of billions of dollars in funding that “enables a wide range of essential healthcare programs, including ones on which vulnerable residents rely.” Additionally, he said, “H&HS’s stated justification for undertaking rulemaking in the first place – a purported ‘significant increase’ in civilian complaints relating to the Conscience Provisions – was factually untrue.” <http://bit.ly/2JZS3J7>

#### Extract from *McKnight’s Senior Living* report

The final rule made several references to abortion but also referred to advanced directives, “assisted suicide, euthanasia, or mercy killing” ... as well as “certain requirements under Medicare and Medicaid that may burden their exercise of their religious beliefs regarding medical treatment.” Elder advocacy group SAGE also noted that some feared that the rule could make it easier to discriminate against LGBTQ individuals.

#### Specialist Publications

‘Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: A scoping literature review’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

‘Adult palliative care in the U.S.: Information-seeking behaviour patterns’ (p.6), in *BMJ Supportive & Palliative Care*.

‘Advertising hospice care services’ (p.6), in *Death Studies*.

## First study of how family religious and spiritual beliefs influence end-of-life care

MEDPAGE | Online – 4 November 2019 – In the first study to investigate the association of the religious and spiritual beliefs of surrogate decision makers with the end-of-life decisions they make for incapacitated older adult family members, researchers have found that surrogate's belief in miracles was the main dimension linked to preferences for care of their loved one.<sup>1</sup> If the surrogate decision maker believed a miracle might occur and change the course of their loved one's illness, the surrogate was more likely to choose aggressive treatment and was less accepting of a comfort-focused care plan. Belief in

miracles was associated with the surrogate decision maker not wanting the patient to have DNR (do not resuscitate) code status. Patients were also less likely to receive hospice services. <http://bit.ly/33sX70p>

### [Specialist Publications](#)

'Spiritual care at the end of life in the primary care setting: Experiences from spiritual caregivers – a mixed methods study' (p.7), in *BMC Palliative Care*.

1. 'The association of surrogate decision makers' religious and spiritual beliefs with end-of-life decisions,' *Journal of Pain & Symptom Management*, published online 27 September 2019. **Abstract (w. link to list of references):** <http://bit.ly/2NGyR43>

Noted in Media Watch 11 March 2019 (#605, p.8):

- **CANCER** | Online – 2 March 2019 – '**A scale to assess religious beliefs in end-of-life medical care.**' Studies postulate that certain religious beliefs related to medical care influence the end-of-life (EoL) medical decision-making... The authors introduce and evaluate the Religious Beliefs in End-of-Life Medical Care scale, a new measure designed to assess religious beliefs within the context of EoL cancer care. The scale consists of 7 items designed to reflect religious beliefs in EoL medical care. The scale proved to be internally consistent, unidimensional, positively associated with other indicators of patients' religiousness and spirituality, and inversely associated with patients' terminal illness understanding and acceptance. **Abstract:** <http://bit.ly/2ITgxFF>

**N.B.** Additional articles on religious beliefs and spiritual aspects of EoL medical decision-making noted in this issue of Media Watch.

## Remove barriers to hospice, palliative care

WASHINGTON DC | *Hospice News* – 4 November 2019 – Stakeholders in the hospice space must work with policymakers to remove barriers that complicate patients' access to care, according to Senator Jackie Rosen – including the requirement for a six-month terminal prognosis. Earlier this year, the Democratic senator from Nevada spearheaded the establishment of the new Comprehensive Care Caucus, a bipartisan group of senators working to expand palliative care (PC) in the U.S. The mission of the caucus is to raise awareness of PC, promote utilization, improve care coordination, support caregivers and expand access to PC services. Among other initiatives, the caucus will likely focus on passage of legislation such as the Provider Training in Palliative Care Act, the Palliative Care and Hospice Education and Training Act and the Rural Access to Hospice Act. These pieces of legislation, respectively, would make PC clinicians eligible to participate in the National Health Service Corps, provide funds for clinician education and public awareness, and allow physicians in Rural Health Centers and Federal Qualified Health Centers to serve as attending physicians for patients in hospice. <http://bit.ly/32jHHdt>

### Related

- **TENNESSEE** | *Hospice News* – 5 November 2019 – '**Tennessee initiative working to expand palliative care.**' The project involves state agencies, hospices and other health care providers, along with healthcare advocacy groups. The effort has its roots in a 2018 state law that established a Palliative Care & Quality of Life Advisory Council, designed to study and raise awareness of palliative care (PC) in Tennessee. The council was born out of the work of a PC task force helmed by the state's Commission on Aging & Disability. Such laws are part of a growing trend among states. As of December 2018, 27 states have laws on their books designed to promote PC, according to the National Academy of State Health Policy. <http://bit.ly/2JU9R8o>

## International

### Ageing prisoners

U.K. | *InsideTime* – 8 November 2019 – Prisoners aged 60 plus are the fastest growing group in Britain’s prisons. As of December 2017, more than 13,500 people aged 50 plus were incarcerated, making up 16% of the entire prison population. That number has trebled in the past 20 years. By 2020, it’s expected to rise to 15,000. The reason for this ageing population is a combination of tougher sentences and the rise in convictions of historic sex offences. The latter means that many are inside for the first time, and struggling with the physical disadvantages that accompany old age. What’s considered “old age” in prison varies significantly from wider society, because any period of incarceration adds around ten years to the physical age of a prisoner. Prisons Inspector Peter Clarke warned the number of men over 50 being held in jails would rise to more than 14,000 by 2022, representing 17% of the prison population. “The Prison Service has so far said that it’s not going to develop an overall strategy to deal with this issue,” he said. “When prisoners get older, less capable physically or infirm, they don’t provide an escape risk, they still have to be held in custody very often and it’s not to say they wouldn’t present a risk to the public if they were completely at liberty. But the question is do they need to be held still in levels of security which are not needed for their physical capabilities and which inevitably are very expensive as well?” The oldest person in prison is a 104 year old man. The obstacles facing this generation of prisoners include: mobility, incontinence, menopause, isolation, dementia, bullying, poverty [state pension is no longer paid upon incarceration] and difficulty adapting upon release. A University of Oxford

study found that more than 80% of male prisoners aged 60 plus suffer a chronic illness or disability. Although there are some palliative care suites across Britain, there aren’t nearly enough to meet demand. <http://bit.ly/2JXRK0X>

### Specialist Publications

**‘Perspectives of health professionals and educators on the outcomes of a national education project in pediatric palliative care: The Quality of Care Collaborative Australia’** (p.13), in *Advances in Medical Education & Practice*.

**‘Providing dignified palliative care services in Liberia’** (p.6), in *Annals of Global Health*.

**‘Hospice-at-home services in England: A national survey’** (p.7), in *BMJ Supportive & Palliative Care*.

**‘Improved quality of death and dying in care homes: A palliative care stepped wedge randomized control trial in Australia’** (p.12), in *Journal of the American Geriatrics Society*.

**‘Why do I have to keep waking up? Terminal sedation and the law in Australia’** (p.10), in *Journal of Law & Medicine*.

**‘End-of-life care among patients with schizophrenia and cancer: A population-based cohort study from the French national hospital database’** (p.12), in *The Lancet: Public Health*.

**‘What does palliative care look like in a New Zealand and aged residential care facility when patients are admitted to die?’** (p.13), in *New Zealand Medical Journal*.

**N.B.** A compilation of selected articles, etc., on end-of-life care in the prison system noted in past issues of Media Watch can be downloaded/viewed from/at the Palliative Care Network website: <http://bit.ly/2RdegnL>



### 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>

## Less than 10% of palliative care needs in Malaysia are being met

MALAYSIA | CodeBlue (Kuala Lumpur) – 6 November 2019 – Currently, Malaysia only has 21 trained palliative medicine specialists, 10 times lower than the required number of 218 for the population. Only seven public hospitals have specialist palliative care (PC) services, of which only four have in-patient PC units, according to the Ministry of Health (MOH). “We want to extend PC centres to Melaka, Negri Sembilan, Sabah, and Sarawak in the next one and a half years,” Dr. Richard Lim, national head of service for palliative medicine at the MOH, told the press at the launch of the National Palliative Care Policy & Strategic Plan 2019-3020... PC needs in Malaysia are projected to increase from 71,675 people in 2004 to 144,454 this year, and to 239,713 in 2030. However, less than 10% of the need is currently being met. The national plan comprises three policy areas: 1) Equity; 2) Sustainability; and, 3) Quality. Seven strategies of the national PC policy are to develop PC as part of universal health coverage, and to identify everyone who needs PC and recognise their needs. <http://bit.ly/32tHJzg>

Noted in Media Watch 26 March 2018 (#556, p.7):

- *ASIAN BIOETHICS REVIEW* | Online – 17 March 2018 – ‘**Considerations for introducing legislation on advance decisions in Malaysia.**’ End-of-life care decision-making is not made easier in a multi-cultural and multi-religious society like Malaysia. Planning for one’s death by making advance decisions can be immensely valuable as it can help healthcare providers in Malaysia to understand better the preferences and wishes of their patients. However, there is currently no specific legislation on any form of advance decisions in Malaysia despite many doctors voicing a need for them. In the absence of legislation, one could look to ethical guidelines, especially from the Malaysian Medical Council, but find that this can sometimes be problematic. **Full text:** <http://bit.ly/2qycNk2>

## Specialist Publications

### Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: A scoping literature review

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2019 – Thirteen studies met inclusion criteria that originated from the U.S., Canada, Scotland, Italy, New Zealand, Ireland, U.K., Korea, and Sweden between years 2003 and 2019. Participants were adults and mostly younger than 64 years, women, and Caucasian. The majority of studies reported the public having poor knowledge (7/9 articles) and awareness (4/6 articles) of palliative care (PC) over the past 16 years. Top characteristics associated with increased levels of knowledge and/or awareness of PC included women (6/8 articles), age 40+ (6/8 articles), experience with a close friend and/or relative requiring PC (4/8 articles), and working in healthcare and/or PC (4/8 articles). The most common perceptions of PC were associated with patients who have terminal illnesses and end-of-life care. Participants commonly received information about PC from the media, having a close friend or relative requiring PC, and working in a health-care setting. The public has poor know-

ledge and awareness about PC and several misperceptions exist. These findings have remained constant over time despite growth in the field of PC, which highlights the strong need for focused educational interventions. **Abstract:** <http://bit.ly/2PTjKa4>

### Publishing Matters

‘**Reporting research findings to participants is an ethical imperative**’ (p.15), *British Medical Journal*.

‘**Reducing the misuse of metrics in research**’ (p.16), Centre for Journalology, Ottawa Hospital Research Institute’

‘**Defining predatory journals and responding to the threat they pose: A modified Delphi consensus process**’ (p.15), in *medRxiv*.

‘**The growth of papers is crowding out old classics**’ (p.17), *Nature Index*.

Cont.

## Related

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 4 November 2019 – ‘**Adult palliative care in the U.S.: Information-seeking behaviour patterns.**’ Acceptance of palliative care (PC) in the U.S. has increased in recent decades with the growing number of recommendations for adoption from professional organisations. However, there are prevalent public misperceptions of PC that may prevent broader utilisation. This study involved 1,127 American adults who were familiar with PC. Overall, American adults rely on healthcare providers and media for PC information, with significant socio-demographic differences in information-seeking behaviour. These findings may be used to inform strategies to promote accurate PC awareness. **Abstract:** <http://bit.ly/2CfRZk7>

**N.B.** Additional articles on awareness of PC in the U.S. noted in 7 October 2019 issue of Media Watch (#634, p.13).

- *DEATH STUDIES* | Online – 8 November 2019 – ‘**Advertising hospice care services.**’ Many hospices advertise their services, yet the audience may frown upon the commercialization of death. The author analyzed the content of 105 American television commercials. The hospices used four major solutions to invite positive readings. They narrated hospices as salvation, provided empowerment, represented hospices as quality service, and appealed to positive values, including comfort and support. Consequently, the commercials used affective advertising to create an emotional appeal where hospices appeared as solutions to difficult life situations. Consequently, the commercials represented both dying and hospices as potentially positive, and marketable experiences. **Full text:** <http://bit.ly/2O8Ckc3>

## Providing dignified palliative care services in Liberia

*ANNALS OF GLOBAL HEALTH*, 2019;85(1):124. Liberia faces a critical shortage of palliative care (PC) services, particularly for persons with advanced-stage HIV/AIDS, tuberculosis, diabetes, and cancers. Access to healthcare services is especially limited in rural areas, along with a lack of supportive social and economic resources. Home of Dignity (HoD) Health Center was established in 2013 in Yarbah's Town to fill a last-option PC gap. The mission emphasizes patient wellbeing and worth. HoD integrates health, agriculture, and education on-site for immediate medical needs, broader sustainable development, and reducing disease-associated stigma in local communities. The Center is providing last-option PC services in the country. As a trusted healthcare center, patients also seek care for acute conditions, resulting in unanticipated resource demands. HoD's experience underscores the need for development of training programs for medical professionals, supply chains, community outreach, and resourcing channels to ensure adequate and sustainable service provision for hospice and PC services and reduce stigma in the country. **Full text:** <http://bit.ly/2JPvAyb>

## Trained facilitators' experiences with structured advance care planning conversations in oncology: An international focus group study within the ACTION trial

*BMC CANCER* | Online – 31 October 2019 – In the ACTION trial, a Phase III multi-center cluster-randomized clinical trial in six European countries (Belgium, Denmark, Italy, The Netherlands, Slovenia, U.K.), patients with advanced lung or colorectal cancer are invited to have one or two structured advance care planning (ACP) conversations with a trained facilitator. Alongside some cultural differences, six themes were identified. These reflect that most facilitators welcomed the opportunity to participate in the ACTION trial, seeing it as a means of learning new skills in an important area. The Respecting Choices script was seen as supportive to ask questions, including those perceived as difficult to ask, but was also experienced as a barrier to a spontaneous conversation. Facilitators noticed that most patients were positive about their ... conversation, which had prompted them to become aware of their wishes and to share these with others. The facilitators observed that it took patients substantial effort to have these conversations. In response, facilitators took responsibility for enabling patients to experience a conversation from which they could benefit. Facilitators emphasized the need for training, support and advanced communication skills to be able to work with the script. **Full text:** <http://bit.ly/2psUJYK>

Cont.

Noted in Media Watch 4 November 2019 (#638, p.13):

- *JOURNAL OF CANCER EDUCATION* | Online – 26 October 2019 – ‘**Advance care planning conversations in the oncology setting: Tips from the experts.**’ Fifty physicians at an oncology hospital, who were identified as having the most advance planning (ACP) conversations, were approached. Major themes were noted and summarized for each of a survey’s 10 questions, resulting in how the physicians can successfully plan for and initiate ACP conversations with their patients and families. Themes touched upon self-awareness, one’s outlook on the value of life, and the importance of death as part of the care continuum. A physician’s own perception of the value of ACP conversations greatly influences them having those conversations. **Abstract (w. list of references):** <http://bit.ly/36cxa8>

### **Spiritual care at the end of life in the primary care setting: Experiences from spiritual caregivers – a mixed methods study**

*BMC PALLIATIVE CARE* | Online – 9 November 2019 – Spiritual caregivers provide care for existential, relational and religious issues, and the emotions related to these issues. Aspects of spiritual care in practice include helping patients find meaning, acceptance or reconciliation, paying attention to the spiritual issues of relatives of the patient, and helping them all to say farewell. Besides spiritual issues, spiritual caregivers also discuss topics related to medical care with patients and relatives, such as treatment wishes and options. Spiritual caregivers also mentioned barriers and facilitators for the provision of spiritual care, such as communication with other healthcare providers, having a relationship of trust and structural funding.. Local multidisciplinary meetings are suggested as ideal opportunities to familiarize other healthcare providers with spirituality and promote spiritual caregivers’ services. Also, structural funding for spiritual caregivers in the primary care setting should be organized. **Full text:** <http://bit.ly/2qBS0fB>

### **Factors associated with non-beneficial treatments in end of life hospital admissions: A multicentre retrospective cohort study in Australia**

*BMJ OPEN* | Online – 4 November 2019 – This is the first study to apply statistical modelling techniques to assess the factors associated with non-beneficial treatment (NBT) in hospital, beyond the intensive care setting. The authors’ data-based approach enabled the objective assessment of various patient and hospital related factors and allowed for the use of statistical tests to inform the generalisability of our results to the population. By analysing data from three major hospitals they were able to examine factors that may influence NBT at the organisational level. While the audit adopted a consensus definition of NBT, this is an inherently subjective and value-laden term and its interpretation may differ between individuals. **Full text:** <http://bit.ly/2CbT8cv>

### **Hospice-at-home services in England: A national survey**

*BMJ SUPPORTIVE & PALLIATIVE CARE* | In Press – 4 November 2019 – There is considerable variation in hospice-at-home services in England. Due to this variation it was not possible to categorise services into delivery types. Services work to supplement local care using a flexible approach benefitting from integration and funding. Further work defining service features related to patient and/or carer outcomes would support future service development. **Abstract:** <http://bit.ly/34OaCrN>

### **Re-defining moral distress: A systematic review and critical re-appraisal of the argument-based bioethics literature**

*CLINICAL ETHICS* | Online – 7 November 2019 – The concept of moral distress comes from nursing ethics, and was initially defined as “...when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.” There is a large body of literature associated with moral distress, yet multiple definitions now exist, significantly limiting its usefulness. Moral distress is most frequently framed around individual experiences of distress in relation to local practices and constraints, and understood in terms of power relations and workplace hierarchies. This understanding is di-

Cont.

rectly derived from, and often still seen as specific to, nursing. Frequently the perspective of the morally distressed individual is privileged. Understandings of moral distress have evolved towards an “occupational health approach,” with the assumption that moral distress should be measured and prevented. Counter-perspectives were identified, highlighting conceptual problems. The authors propose a redefinition of moral distress: “Ethical unease or disquiet resulting from a situation where a clinician believes they have contributed to avoidable patient or community harm through their involvement in an action, inaction or decision that conflicts with their own values.” This definition is specific enough for research use, anchored in clinicians’ professional responsibilities and concerns about harms to patients, framed relationally rather than hierarchically, and amenable to multiple perspectives on any given morally distressing situation. **Abstract:** <http://bit.ly/2p13vwP>

### **Barriers and facilitators to a “good death” in heart failure: An integrative review**

*COLLEGIAN* | Online – 2 November 2019 – Heart failure (HF) is the final common pathway of many cardiovascular diseases, and yet many individuals with HF die hospitalised, suffering needlessly and experiencing what could be termed a “bad death.” While it is essential to address the wishes of individuals and their families in improving the quality of end-of-life care (EoLC) for patients with HF, their unmet needs remain poorly understood. Five themes associated with EoLC in HF and a good death were generated: 1) Location of death; 2) Preferred care; 3) Palliative care utilisation; 4) Interventions to improve the likelihood of a good death; and, 5) The intersection of individual, family, healthcare providers, and community-level factors. This review identifies modifiable barriers and facilitator of a good death and emphasised the importance of considering the intersection of patient, provider and healthcare system issues in facilitating a good death for patients with HF. **Abstract (w. link to list of references):** <http://bit.ly/34pvipl>

#### **Related**

- *AMERICAN JOURNAL OF THERAPEUTICS* | Online – 25 October 2019 – ‘**Palliative care in heart failure: A public health emergency.**’ Patients with heart failure (HF) are the largest group eligible for palliative care (PC) services, but only a small percentage of them receive PC. Because of the unpredictability of the disease and difficulty in prognostication, PC should be introduced at the point of diagnosis of HF. Basic education in PC needs to be introduced early in the training of cardiology staff, focused on concept definition, differentiating PC and terminal care, symptom management, communication, and decision-making. Research concerning PC in HF is still scarce and comes predominantly from developed countries. **Abstract:** <http://bit.ly/2WS14Jc>

**N.B.** Additional articles on palliative and end-of-life care for patients living with HF noted in 21 October 2019 issue of *Media Watch* (#636, p.17).

### **Potential unintended consequences of recent shared decision making policy initiatives**

*HEALTH AFFAIRS*, 2019;38(11):1876-1881. Shared decision making (SDM) ... is moving swiftly from an ethical ideal toward widespread clinical implementation affecting millions of patients through recent policy initiatives. The authors argue that policy initiatives to promote SDM implementation in clinical practice carry the risk of several unintended negative consequences if limitations in defining and measuring SDM are not addressed. They urge policy makers to include prespecified definitions of desired outcomes, offer guidance on the tools used to measure SDM in the multitude of contexts in which it occurs, evaluate the impact of SDM policy initiatives over time, review that impact at regular intervals, and revise SDM measurement tools as needed. **Abstract:** <http://bit.ly/2NmhvKZ>

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Noted in Media Watch 29 April 2019 (#612, p.7):

- *JOURNAL OF AMERICAN MEDICAL ASSOCIATION* | Online – 19 April 2019 – ‘**Shared decision making and the importance of time.**’ Clinical decisions may involve screening or treatment with new toxic drugs in older patients; timely use of adjuvant, palliative, or pain care; or prioritizing care at the end of life. Shared decision making is essential in the care of patients in these complicated situations. For clinicians, being able to and choosing to spend time on understanding what truly matters to patients when making decisions together is an achievement that makes the work of clinicians meaningful and rewarding. The most common barrier to shared decision making, cited by patients and clinicians, is time. **Full text:** <http://bit.ly/2XANLMS>

Noted in Media Watch 19 March 2018 (#555, p.10):

- *JOURNAL OF BIOETHICAL INQUIRY* | Online – 14 March 2018 – ‘**Can the ethical best practice of shared decision-making lead to moral distress?**’ When healthcare professionals feel constrained from acting in a patient’s best interests, moral distress ensues. The resulting negative sequelae of burnout, poor retention rates, and ultimately poor patient care are well recognized across healthcare providers. Yet an appreciation of how particular disciplines, including physicians, come to be “constrained” in their actions is still lacking. This paper examines how the application of shared decision-making may contribute to the experience of moral distress for physicians and why such distress may go under-recognized. **Abstract (w. list of references):** <http://bit.ly/2PTN3JQ>

### **Barriers [in the U.S.] to palliative and hospice care utilization in older adults with cancer: A systematic review**

*JOURNAL OF GERIATRIC ONCOLOGY* | Online – 4 November 2019 – The number of older adults with cancer and the need for palliative care among this population is increasing in the U.S. The objective of this systematic review was to synthesize the evidence on the barriers to palliative and hospice care utilization in older adults with cancer. Nineteen studies were synthesized in this review. Barriers to palliative and hospice care utilization were categorized into socio-demographic barriers, provider-related barriers, and health insurance-related barriers. Findings revealed that male, racial minority, unmarried individuals, individuals with low socio-economic status or residing in rural areas, and fee-for-service enrollees were less likely to use palliative or hospice care. Lack of communication with care providers is also a barrier of using palliative or hospice care. The factors identified in this review provide guidance on identification of high-risk population and intervention development to facilitate the use of palliative and hospice care in older adults with cancer. Larger prospective studies on this topic are needed to address this critical issue.

**Abstract:** <http://bit.ly/32oL96x>

### **A doctor’s discretion not to offer life-sustaining treatment**

*JOURNAL OF LAW & MEDICINE* | Online – Accessed 5 November 2019 – A doctor may make a unilateral decision to withdraw or withhold life-sustaining treatment from a patient. Recent cases involving critically ill children in Australia, England and Wales have demonstrated how doctors may determine a child’s life is not worth maintaining despite parental demands for treatment. The breadth of a doctor’s discretion to not provide treatment is ambiguous though, and the extent to which a doctor may make unilateral quality of life judgments is not clear. The ambiguity arises because of different framing of a doctor’s obligations, a lack of clear role delineation between relevant decision-makers and differences in opinion about the appropriate scope of inquiry when applying concepts like “futility” and “best interests”. This ambiguity is likely to cause confusion in practice and may be the difference between a child receiving life-sustaining treatment. **Download/view abstract at:** <http://bit.ly/36Anlu5>



### Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.17.

## Why do I have to keep waking up? Terminal sedation and the law in Australia

*JOURNAL OF LAW & MEDICINE* | Online – Accessed 5 November 2019 – Professional guidelines for palliative care restrict terminal sedation use to within a few days of death. The law relating to its use in Australia is governed by the law of homicide, assisted suicide and the law of trespass. The author argues that the law does not justify the restrictions on its use imposed by the professional guidelines, and that, ethically and legally, it can be made available to patients with a terminal disease, those who are likely to suffer serious physical or existential pain by remaining conscious, and for those who refuse food and water. Its use should be regulated to ensure that those asking for it are competent to do so, and that they are suffering from a medical condition that makes life intolerable for them. **Download/view abstract at:** <http://bit.ly/36Anlu5>

**N.B.** Additional articles on terminal (or palliative) sedation noted in 28 October 2019 issue of Media Watch (#637, p.11).

## Public views about quality of life and treatment withdrawal in infants: Limitations and directions for future research

*JOURNAL OF MEDICAL ETHICS* | Online – 2 November 2019 – Work done within the realm of what is sometimes called “descriptive ethics” brings two questions readily to mind: ‘How can empirical findings, in general, inform normative debates?’ and ‘How can these empirical findings, in particular, inform the normative debate at hand?’ Brick *et al* confront these questions in their novel investigation of public views about lives worth living and the permissibility of withdrawing life-sustaining treatment from critically ill infants.<sup>1</sup> Mindful of the is-ought gap, the authors suggest modestly that their data “may be useful when constructing guidelines for clinical practice.” In this commentary, the author considers some potential limitations on the generalisability of these data in the context of policy and clinical practice, limitations which may in turn serve as directions for future empirical research. The authors’ study presents six case scenarios, five of which involved the possibility of withdrawing life-sustaining treatment from critically ill infants. The results revealed that “[a]lmost all respondents agreed that at some level of quality of life, life may be of no benefit or worse than death for an infant” and that “participants significantly favoured withdrawal of treatment for the most severe cases.” **Introductory paragraphs:** <http://bit.ly/2JFT9tl>

1. ‘Worth living or worth dying? The views of the general public about allowing disabled children to die,’ *Journal of Medical Ethics*, published online 15 October 2019. [Noted in 21 October 2019 issue of Media Watch (#636, p.13)] **Full text:** <http://bit.ly/2Bf1HTh>

### Related

- *JOURNAL OF LAW & MEDICINE* | Online – Accessed 5 November 2019 – ‘**An objective approach to decisions to withdraw or withhold life-sustaining medical treatment.**’ Courts in England & Wales, Australia and New Zealand insist the question of when it is acceptable to withdraw or withhold life-sustaining medical treatment from a child must be considered on a case-by-case basis. This review demonstrates that there are factors consistently identified and despite criticisms of the indeterminacy of the best interests test, there may be a broadly consistent approach to decision-making. Cognitive capacity and unavoidably imminent death appear to be the two most influential factors in determining whether life-sustaining treatment should be provided. **Download/view abstract at:** <http://bit.ly/36Anlu5>

Noted in Media Watch 28 October 2019 (#637, p.10):

- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 22 October 2019 – ‘**In the child’s best interests: Should life be sustained when further treatment is futile?**’ There have been several recent cases where medical staff have considered that there was no possibility of recovery for a child, yet their clinical judgments were challenged by the parents. The private anguish of these families became public, social media heightened emotions and this was followed by political and religious intrusion. Healthcare professionals have a moral and legal obligation to determine when treatment should cease in cases where it is determined to be futile. The aim should be to work collaboratively with parents but all decisions must be made in the best interests of the child. **Abstract:** <http://bit.ly/2oWlfbD>

## **Design and preliminary testing of the Caregiver-Centered Communication Questionnaire (CCCQ)**

*JOURNAL OF PALLIATIVE CARE* | Online – 7 November 2019 – The authors developed a questionnaire inspired by the National Cancer Institute framework on patient-centered communication, focusing on family caregiver communication for this tool. The questionnaire includes 5 sub-scales: 1) Exchange of information; 2) Relationship with team; 3) Emotions; 4) Managing care; and, 5) Decision-making. The initial questionnaire was reviewed by domain experts for face validity and edited further to include 30 items. The authors administered the modified questionnaire to 115 family caregivers (FCGs) of patients with serious illness in various settings. Participants found that the survey addressed important concepts and that items were in most cases easy to understand. This instrument provides a structured way to assess caregiver-centered communication, addressing a pressing need for tools that measure the extent to which communication is responsive to the needs and preferences of FCGs. **Abstract:** <http://bit.ly/2pSITHq>

## **Top ten tips palliative care clinicians should know about psychosocial and family support**

*JOURNAL OF PALLIATIVE MEDICINE* | Online – 5 November 2019 – Palliative care (PC) is perhaps the most inherently interdisciplinary specialty within healthcare. Comprehensive PC is delivered by a core team of physicians, nurses, social workers, spiritual care providers, pharmacists, and others who address the broad range of medical, psychosocial, and spiritual needs of those living with serious illness. While PC clinicians are typically skilled in screening for distress, the best path to follow when patients screen positive for psychosocial distress or exhibit mental health challenges may not always be clear. This article brings together the perspectives of experienced social workers practicing across PC and hospice settings. It seeks to identify opportunities and rationale for the integration of palliative social work (PSW) in the provision of quality, person-centered, family-focused, and culturally congruent care for the seriously ill. Increasing recognition of the impact of social determinants of health highlights the critical importance of including PSW if we are to better understand and ultimately address the broad range of factors that influence people's quality of life. **Abstract:** <http://bit.ly/36ytgW6>

Noted in Media Watch 25 May 2019 (#607, p.12):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 20 March 2019 – **'Results of a nationwide hospice and palliative care social work job analysis.'** The role of the hospice and palliative social worker is often ambiguous and misunderstood by colleagues and fellow team members. One reason for this is the lack of identified, clearly delineated roles, skills, and tasks employed by these specialty social workers in their daily work. This article summarizes the first nationwide job analysis of hospice and palliative social workers. Tasks were categorized into four broad categories: 1) Assessment and re-evaluation; 2) Planning and intervention; 3) Death, grief, and bereavement; and, 4) Professionalism. **Abstract:** <http://bit.ly/2WhBkET>

**N.B.** Additional articles on the role of social workers in the context of hospice and palliative care.

## **A multicenter study to identify clinician barriers to participating in goals-of-care discussions in long-term care**

*JOURNAL OF POST-ACUTE & LONG-TERM CARE MEDICINE* | Online – 28 October 2019 – In this study, the highest-rated clinician barriers to goals-of-care (GoC) discussions related to the lack of preparedness of long-term care (LTC) residents and power of attorneys (POAs) to have GoC discussions, specifically, the power of POAs' difficulty accepting the LTC resident's poor prognosis, and their difficulty understanding the limitations and complications of life sustaining therapies. System-level barriers identified by nursing respondents related to poor documentation of previous conversations and the lack of time to engage in proper GoC discussions with residents and their POAs. Developing interventions that target the most important common barriers could form the foundation of local quality improvement initiatives. The results of these initiatives could impact policies at the local and corporate LTC level, and other policy makers to support high-quality GoC discussions in LTC. **Full text:** <http://bit.ly/2Nc27jW>

Cont.

## Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 4 November 2019 – ‘**Improved quality of death and dying in care homes: A palliative care stepped wedge randomized control trial in Australia.**’ Palliative Care Needs Rounds are monthly hour-long staff-only triage meetings to discuss residents at risk of dying without a plan in place. They are chaired by a specialist palliative care clinician and attended by care home staff. This article reports secondary outcomes of staff perceptions of residents’ quality of death and dying, care home staff confidence, and completion of advance care planning documentation. The authors’ findings offer evidence for monthly triage meetings to transform the lives, deaths, and care of older people residing in care homes. **Abstract:** <http://bit.ly/2JR0Lt2>

**N.B.** A selection of articles on palliative and end-of-life care in LTC, from past issues of Media Watch, noted in October issue of the International Association for Hospice & Palliative Care’s newsletter [scroll down to ‘Media Watch: Long-Term Care’] at: <http://bit.ly/2p0p68g>

### **Palliative care for patients with advanced chronic kidney disease: Moving beyond the *status quo***

*KIDNEY MEDICINE* | Online – 1 November 2019 – Recognition of the need for integrating palliative care (PC) in nephrology has increased dramatically over the past decade. The authors have noticed a progressive conceptual awareness amongst their colleagues in both fields – influenced, no doubt, by studies revealing disparities in the quality of end-of-life care for patients with chronic kidney disease (CKD) – that integrating PC principles and practices can address key areas of unmet need in advanced CKD and end stage renal disease (ESRD) care: high symptom burden; insufficient advance care planning; poor utilization of hospice care; and, limited communication skills training for nephrology providers. What is necessary now is the development of sustainable renal PC models for patients with advanced kidney disease. The recent Executive Order on Advancing American Kidney Health echoes this need for macro-level change to address high mortality, limited communication, and poor quality of life in CKD and ESRD, emphasizing the prioritization of patient and provider education, expansion of treatment options beyond dialysis alone, and introduction of new payment models. **Full text:** <http://bit.ly/2Nk5ipY>

**N.B.** Additional articles on palliative and end-of-life care for people living with CKD noted in 2 September 2019 issue of Media Watch (#629, p.10).

### **End-of-life care among patients with schizophrenia and cancer: A population-based cohort study from the French national hospital database**

*THE LANCET: PUBLIC HEALTH*, 2019;4(11):PE583-PE591. Patients with schizophrenia represent a vulnerable, underserved, and undertreated population who have been neglected in health disparities work. Understanding of end-of-life care (EoLC) in patients with schizophrenia and cancer is poor. The authors divided the patient population studied into cases (i.e., patients with schizophrenia) and controls (i.e., patients without a diagnosis of mental illness) and compared access to palliative care (PC) and indicators of high-intensity EoLC between groups. The main analysis included 2,481 patients with schizophrenia and 222,477 controls. Patients with schizophrenia were more likely to receive PC in the last 31 days of life ... and less likely to receive high-intensity EoLC – such as chemotherapy and surgery – than were matched controls without a diagnosis of mental illness. **Full text:** <http://bit.ly/2N9IF7G>

Noted in Media Watch 3 December 2018 (#592, p.14):

- *PLOS ONE* | Online – 29 November 2018 – ‘**Morbidity burden and community-based palliative care are associated with rates of hospital use by people with schizophrenia in the last year of life: A population-based matched cohort study.**’ People with schizophrenia who are dying with conditions amenable to palliative care (PC) are half as likely to receive specialist PC in the home compared to a matched cohort. Decedents with schizophrenia were just as likely to have accessed non-palliative community-based services in the last year of life as decedents without schizophrenia. Studies from countries with universal healthcare have also reported regular and increased access to GP services by people with schizophrenia. **Full text:** <http://bit.ly/2Ca9EcM>

**N.B.** Additional articles on EoLC for people living with schizophrenia noted in this issue of Media Watch.

## **What does palliative care look like in a New Zealand aged residential care facility when patients are admitted to die?**

*NEW ZEALAND MEDICAL JOURNAL*, 2019;132(1505):14-28. New Zealanders dying in public hospitals or hospices are increasingly being discharged and admitted-to-die in aged residential care (ARC) facilities as hospitals and hospices struggle to meet demand. The clinical notes review [of seven patients who died in one ARC facility within three months of admission] showed a high burden of palliative care (PC) symptoms that constituted specialist PC, provided by ARC staff plus professionals from other organisations. Focus group data showed those involved were willing, but expressed significant concern about lack of structure and funding. As the country's increasing and aging population reaches end-of-life, hospitals/hospices will not be able to provide ongoing specialist PC and admission-to-die in ARC facilities may be a viable alternative. ARC facilities are not set up or staffed to provide specialist PC of those admitted-to-die. A specific model of care that is funded appropriately is required. **Abstract:** <http://bit.ly/34CWcKE>

## **Insights into the perception that research ethics committees are a barrier to research with seriously ill children: A study of committee minutes and correspondence with researchers studying seriously ill children**

*PALLIATIVE MEDICINE* | Online – 4 November 2019 – The aim of this study was to explore committees' concerns, expectations and decisions for research applications involving seriously ill children submitted for review in the U.K. The authors' findings suggest that committees review applications for research involving seriously ill children with the same scrutiny as applications for research with other populations. Yet, the perception that committees act as a barrier to this type of research persists. The authors suggest that this perception remains due to other factors including, but not limited to, the high levels of formatting or administrative revisions requested by committees or additional study requirements needed for research involving children, such as multiple versions of consent forms or participant information sheets. **Abstract:** <http://bit.ly/34pkoQO>

## **Core outcome domains of pediatric palliative care for children with severe neurological impairment and their families: A qualitative interview study**

*PALLIATIVE MEDICINE* | Online – 4 November 2019 – The interest in outcome measurement in pediatric palliative care (PC) is rising. To date, the majority of studies investigating relevant outcomes of pediatric PC focus on children with cancer. Insight is lacking, however, about relevant outcome domains for children with severe neurological impairment and their families. The aim of this study was to identify meaningful outcome domains of pediatric PC for children with severe neurological impairment and their families. Ten cooperating pediatric PC institutions across Germany (outpatient and inpatient settings) aided in the recruitment of eligible parents and professional caregivers. Six core outcome domains of pediatric PC for children with severe neurological impairment and their families were identified: 1) Symptom control; 2) Respite and support; 3) Normalcy; 4) Security; 5) Empowerment; and, 6) Coping with the disease, each consisting of 1 to 13 individual aspects. As for other diagnostic groups, symptom control is a relevant outcome domain for children with severe neurological impairment. However, other outcome domains which focus on the whole family and take into account the long disease trajectory, such as respite and support, security, empowerment, and coping with the disease, are also crucial. **Abstract:** <http://bit.ly/2NQM9ez>

### **Related**

- *ADVANCES IN MEDICAL EDUCATION & PRACTICE* | Online – 7 November 2019 – '**Perspectives of health professionals and educators on the outcomes of a national education project in pediatric palliative care: The Quality of Care Collaborative Australia.**' Demand for generalist health professional knowledge and skills in pediatric palliative care (PPC) is growing in response to heightened recognition of the benefits of a palliative approach across the neonatal, pediatric, adolescent and young adult lifespan. This study contributes to a growing body of knowledge on innovative and responsive mechanisms for enhancing workforce capability in PPC and provides additional evidence to support funding of dedicated educator roles in specialist PPC services. **Full text:** <http://bit.ly/2CnA2Ak>

Cont.

- *PALLIATIVE MEDICINE* | In Press – Accessed 7 November 2019 – ‘**Finding a way with words: Delhi study to develop a discussion prompt list for paediatric palliative care.**’ Effective communication is a cornerstone of quality paediatric palliative care (PC). Families report struggling, however, to know what to discuss, with whom, and when. Although question prompt lists exist for adult PC, they do not suit the unique circumstances of paediatric PC. Through multi-phase consultation across participant groups, the draft question prompt list was refined progressively to 28 items, split across two booklets to allow end-of-life items to be provided separately, and re-conceptualised as a discussion prompt list rather than a question prompt list. **Abstract:** <http://bit.ly/33t8rJU>

### **Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling**

*RESEARCH & PRACTICE FOR PERSONS WITH SEVERE DISABILITIES* | Online – 30 October 2019 – People with people with profound intellectual and multiple disability (PIMD) are living longer lives than ever before. Therefore, they are increasingly facing decisions relating to end-of-life (EoL) care and planning. Despite the increased attention that has been given to EoL planning, opportunities to have preferences responded to at the EoL are more likely afforded to people considered to have cognitive and decision-making capacity. Those supporting people with PIMD to plan for and make decisions about EoL care face several challenges. These challenges are rooted in difficulties with communication exchange between people with PIMD and their communication partners, leading to a widely held perception of decision-making incompetence for this population. This article draws on empirical research to discuss decision-making support within the context of palliative care and advance care planning, specifically for people with PIMD. It promotes decision-making support as an approach to assist supporters of people with PIMD to allow those people’s expressions of preferences to be acknowledged and acted upon at the EoL. The use of narrative is presented and discussed as a tool for enabling this responsiveness, specifically within the context of EoL planning. **Full text:** <http://bit.ly/33dWebJ>

**N.B.** Additional articles on palliative and EoL care for people living with intellectual and developmental disabilities noted in 21 October 2019 issue of Media Watch (#636, p.7).

### **Assisted (or facilitated) death**

Representative sample of recent journal articles:

- *CANADIAN JOURNAL OF BIOETHICS*, 2019;2(2). ‘**Conscientious objection to medical assistance in dying: A qualitative study with Quebec physicians.**’ Patients in Quebec can legally obtain medical assistance in dying (MAiD) if they are able to give informed consent, have a serious and incurable illness, are at the end of their lives and are in a situation of unbearable suffering. Since the Supreme Court of Canada’s 2015 Carter decision, access to MAiD, under certain conditions, has become a constitutional right. Quebec physicians are now likely to receive requests for MAiD from their patients. The Quebec and Canadian laws recognize a physician’s right to conscientious objection, but this right is contested both in the medical ethics literature and in the public sphere. This article presents the results of a qualitative study conducted with twenty Quebec physicians who did not integrate MAiD into their medical practice, either because they were opposed to or deeply ambivalent about MAiD. The interviews aimed to explore the reasons – religious and secular – for opposition to or ambivalence towards MAiD. The secular reasons given by participants were grouped into four main categories: 1) The ends of medicine and professional identity; 2) The philosophy of palliative medicine and resource allocation in palliative care; 3) Benevolent paternalism, the “good death,” and the interests of future selves; and, 4) The risk of a slippery slope and the protection of vulnerable people. **Abstract:** <http://bit.ly/32tu23B>
- *TEACHING & LEARNING IN MEDICINE* | Online – 4 November 2019 – ‘**Medical assistance in dying: A point-of-care educational framework for attending physicians.**’ Medical assistance in dying (MAiD) became legal in Quebec in December 2015, and in the rest of Canada in June 2016. While the death of a patient is a common experience for medical trainees, those that occur through MAiD have unique features related to the methods, the timeline, the intended role of the physician in causing the death, and the request of the patient that initiates the process. These aspects necessitate a distinct approach to MAiD medical education. Despite the legalization of MAiD in a growing number of jurisdic-

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tions, there is virtually no literature to guide MAiD education in clinical practice. The cumulative evidence regarding the impact of patient death on medical students, residents, and attending physicians suggests a need for supported discussion and debriefing to process and reflect on the emotional experiences that follow patient death. This is especially important with MAiD, in which there are unique ethical and psychological issues related to the physician's direct role in causing the death of a patient. The authors created a framework to guide learning at the point of care of a patient requesting MAiD. Represented in a MAiD Education Cogwheel and discussion guide, this framework specifies learning objectives and methods in six domains... Following a MAiD request, attending physicians can use the framework to guide learners in ongoing conversations addressing these domains. Inter-professional participation can include such disciplines as psychiatry, palliative care, bioethics, pharmacy, nursing, physical and occupational therapy, social work, and spiritual care. **Abstract:** <http://bit.ly/36CZdfN>

## [Publishing Matters](#)

### **Reporting research findings to participants is an ethical imperative**

*BRITISH MEDICAL JOURNAL* | Online – 4 November 2019 – The results of clinical trials should be disseminated to those who took part in them. For a start, it is a basic courtesy, and that should be reason enough. It is also an ethical imperative. The World Medical Association's Declaration of Helsinki insists that "all medical research subjects should be given the option of being informed about the general outcome and results of the study." Research subjects contribute to the greater good and expose themselves to risk of harm. They have a right to know the outcome of the research. This is especially important for participants with a direct interest in the findings, for whom knowledge can be power. Reporting back to participants is part of the discipline of transparency that keeps researchers honest and accountable. It fits with the broader responsibility of scientists to communicate their work and foster public understanding. It is part of making patient and public involvement a core strand of health research. It is consistent with a welcome focus on lay summaries, shortly to become mandatory as part of the European Union clinical trials directive. **Full text:** <http://bit.ly/2WFT9yJ>

### **Defining predatory journals and responding to the threat they pose: A modified Delphi consensus process**

*MEDRxIV* | Online – 2 November 2019 – Posing as legitimate open access outlets, predatory journals and publishers (PJ&P) threaten the integrity of academic publishing by not following publication best practices. Currently, there is no agreed upon definition of predatory journals, making it difficult for funders and academic institutions to generate practical guidance or policy to ensure their members do not publish in these channels. Forty-five participants [an international group of academics, funders, policy makers, journal editors, publishers] completed a survey on (PJ&P). Consensus was reached on 18 items out of a total of 33, to be included in a consensus definition of (PJ&P). Participants came to consensus on educational outreach and policy initiatives on which to focus, including the development of a single checklist to detect (PJ&P), and public funding to support research in this general area. Identified were technological solutions to address the problem: a "one-stop-shop" website to consolidate information on the topic and a "predatory journal research observatory" to identify ongoing research and analysis about (PJ&P). In bringing together an international group of diverse stakeholders, the authors were able to use a modified Delphi process to inform the development of a definition of (PJ&P). This definition will help institutions, funders and other stakeholders generate practical guidance on avoiding (PJ&P). **Abstract:** <http://bit.ly/2JRYwFF>



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



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

# Reducing the misuse of metrics in research

Dr. Stefanie Haustein recently spoke as part of The Ottawa Hospital's Centre for Journalology Speaker Series. Below are some key messages from Dr. Haustein's talk.

## What is the impact factor?



The impact factor is an average citation rate of a journal, where the citations received in one year are divided by the number of documents published in the two previous years. It was invented by Eugene Garfield in the 1960s to select journals to include in the Science Citation Index and has since then become synonymous with journal prestige and scientific impact. The impact factor has several flaws including its asymmetry in its calculation, where citations to all documents are included in the numerator but only so-called citable items (i.e., articles and reviews) are counted in the denominator.

## Does a journal impact factor predict the future citation impact of my papers?



The impact factor represents the average number of citations per publication. However, as the arithmetic mean of a skewed distribution, it is not a good predictor of citation impact on the article level. For example, when you publish in a journal with an impact factor of 10.513, your paper might receive less than 10 citations (or even none at all) or could very well be cited hundreds of times. As a journal indicator, the impact factor is therefore a bad proxy on the level of individual papers or researchers.

## Should I be using h-index as an indicator?

The h-index, invented by the physicist Jorge E. Hirsch in 2005, to quantify an author's research output and impact, is defined as "index h if h of [a scientist's]  $N_p$  papers have at least h citation each and the other ( $N_p - h$ ) papers have  $\leq h$  citations each"[1]. It is an inconsistent indicator because it violates several properties, for example, if two scientists achieve the same relative performance improvement, their ranking relative to each other should remain unchanged. When two authors receive the same number of citations, their h-index should increase accordingly. However, the h-index of one author might go up, while the other one's stays the same. Due to these inconsistencies "the h-index cannot be considered an appropriate indicator of the overall scientific impact of a set of publications"[2].

## What adverse effects do scholarly metrics have on the scholarly community?

With bibliometric indicators based on the number of publications and citations having become prevalent in research funding, tenure and promotion decisions, certain adverse effects can be observed. For example, in order to appear as more productive, researchers have started to publish several instead of one article. This tactic to artificially increase publication counts has been coined "salami" publishing. Honorary authorship is another strategy to increase publication counts. Artificially increasing citation rates can be achieved through excessive self-citing or citation cartels. The latter is particularly popular on the level of journals, where editors arrange to cite each other's recent issues to increase the journals' impact factors.

1. Hirsch, J.E. (2005). An index to quantify an individual's scientific research output. *Proceedings of the National Academy of Sciences of the United States of America*, 102(46), 16569-16572.

2. Waltman, L. & van Eck, N.J. (2012). The inconsistency of the h-index. *Journal of the American Society for Information Science and Technology*, 63(2), 406-415.



Questions?

Contact the Centre for Journalology via Dr. Kelly Cobey.





## The growth of papers is crowding out old classics

*NATURE INDEX* | Online – 4 November 2019 – Freshly published and very old articles are missing out on citations as researchers try to stay abreast of the rapidly growing scientific literature, an analysis of more than 32 million papers reveals. An analysis led by Raj Kumar Pan, a computer scientist at Alto University in Finland, found that the number of academic papers is increasing by 4% each year. The total number of citations is growing by 5.6% each year, and doubling every 12 years. According to Alexander Petersen, co-author of the study, this huge volume of new articles isn't just reshaping scientific publishing, it's also changing how researchers "follow the reference trail." Rather than sift through large volumes of new papers, researchers are opting for middle-aged articles that have gained greater visibility and more citations. "The deluge of new literature is crowding out old literature," says Petersen, a computational social scientist at the University of California. **Full text:** <https://go.nature.com/32fKKTV>

### 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.

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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.

### Media Watch: Access on Online

#### International



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2NqALqN>

[Scroll down to 'Media Watch: GPs & Quality of Care']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

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PALLIATIVE CARE NETWORK: <http://bit.ly/2Ujdk2S>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU> ]

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

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

#### **Canada**



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

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#### **Europe**



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2XC24jA>

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>

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