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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Compilation of Media Watch 2008-2018 ©

Compiled & Annotated by Barry R. Ashpole

Living with a life-threatening disease: Scroll down to <u>Specialist Publications</u> and 'Is blogging a new form of communication in palliative health care? A qualitative research study' (p.10), in *International Journal of Palliative Nursing*.

Canada

Family Perspectives: Death & Dying in Canada

THE VANIER INSTITUTE OF THE FAMILY | Online - 7 May 2018 - Death is a natural part of life, but many Canadians are hesitant to have essential conversations about the end of their lives. This study is "a conversation catalyst" to spark dialogue in households, workplaces and communities across the country by exploring death and dying through a family lens. It examines the evolution of death and dying in Canada across generations, the desires and realities of families surrounding death and dying, their role in end-of-life care and its impact on well-being. Through data and trend analysis, interviews with caregivers and families, and reflections on hospice volunteering, the author discusses death and dying within the current and emerging social, cultural and policy landscapes. "While many people are hesitant to talk about death and dying with their families and health care providers, some of the silence surrounding death and dying in Canada has been broken - a step in the right direction. Talking about death with family, planning for what we hope for and supporting others can help us to see that death is a natural part of life that is not inherently undignified, and to appreciate the present, thereby enriching our lives," says the author Katherine Arnup a retired Carleton University professor. **Download/view** at: <u>https://goo.gl/wBV197</u>

Extract from Vanier Institute study

Today, many needs of families facing illness and the death of a loved one remain unmet. Home care and palliative care services are unavailable or woefully inadequate for the vast majority of Canadian families. Bereavement leave and support are rare and insufficient in a culture that urges us to get back to work following the death of a loved one within a day or two. While death may be a medical fact of life, death is also a human issue, a social issue, and issue that impacts each and every one of us.

Specialist Publications

'Language barriers restricting access to health care for Indigenous populations' (p.9), in *Canadian Medical Association Journal.*

Assisted (or facilitated) death

Representative sample of recent news media coverage:

QUEBEC | CBC News (Montreal) – 31 May 2018 – 'Lack of palliative care pushing Quebecers toward medically assisted death, College of Physicians says.' A lack of palliative care (PC) services in parts of Quebec may be forcing patients to choose medical aid in dying (MAiD) as a way to end their lives with dignity, says Quebec's College of Physicians. In a letter sent to Quebec Health Minister Gaétan Barrette this week, the group said Quebec is suffering from a lack of specialized, PC doctors and uneven levels of service are being offered across the province. "Patients, failing to benefit from such care, could have had no other choice but to ask for MAiD to end their days in dignity," the letter reads. The college said patients requesting MAiD are getting priority access to available resources, "to the detriment of other patient" at the end of their lives. "PC cannot be limited to access to MAiD," its letter reads. The group's president, Dr. Charles Bernard, said fewer physicians and medical professionals have chosen to specialize in PC over the last two years. https://goo.gl/bcvvy1

<u>U.S.A.</u>

Four women sue Idaho over law that voids your living will if you're pregnant

IDAHO | *The Idaho Statesman* (Boise) – 31 May 2018 – Under Idaho law, if a woman has a directive for end-of-life care, it becomes invalid if she is pregnant. Four Idaho women are challenging this law, saying it violates people's constitutional rights to legal equality and to direct their own medical care. Idaho's Medical Consent & Natural Death Act provides for "the fundamental right of competent persons to control the decisions relating to the rendering of their medical care, including the decision to have life-sustaining procedures withheld or withdrawn." But the law states that if a person has "been diagnosed as pregnant, this Directive shall have no force during the course of pregnancy." <u>https://goo.gl/JsDF25</u>

Specialist Publications

'Filling the gap: Creating an outpatient palliative care program in your institution' (p.8), in *ASCO Educational Book.*

"How much time do I have?": Communicating prognosis in the era of exceptional responders' (p.8), in *ASCO Educational Book*.

'Beyond legalization – dilemmas physicians confront regarding aid in dying' (p.15), in *The New England Journal of Medicine*.

Trump signs "right-to-try" allowing gravely ill patients to bypass Food & Drug Administration for experimental medicines

WASHINGTON DC | CNBC News – 30 May 2018 – President Donald Trump signed the controversial "right-to-try" bill into law, which bypasses drug regulators to give gravely ill patients access to experimental medicines. The legislation allows patients with life-threatening conditions to ask drug makers for medicines that have cleared some testing but still haven't been approved by the Food & Drug Administration (FDA). Previously, people would need to ask the FDA for access to experimental treatments. The House of Representatives approved the bill last week, which is the same version the Senate passed in August. It allows certain patients to ask drug makers for medicines that have passed Phase 1 of the FDA approval process, but haven't been approved yet and are still undergoing testing. Patients must have exhausted other options and be unable to participate in a clinical trial. Drug makers aren't obligated to give patients the requested experimental medicines. Critics say the legislation undermines the FDA's authority to regulate drugs and could leave patients vulnerable to medicines that might not work or even be harmful. The agency already runs an "expanded access" program where seriously ill patients can apply to gain access experimental treatments. https://goo.gl/ouYX5w Noted in Media Watch 12 February 2018 (#550, p.5):

- TIME MAGAZINE | Online 5 February 2018 'Terminally ill people want more access to experimental treatments. Here's why doctors are pushing back.' Right-to-try laws have passed in some 38 states. While no one wants to argue against giving potentially beneficial drugs to people who need them, not everyone in the medical community is convinced a national right-to-try policy will ultimately make life better for patients. https://goo.gl/3VfEGD
- N.B. Additional articles on "right-to-try" laws noted in 29 January 2018 issue of Media Watch (#548, p.11).

Hospice employees hope legislation will allow on-site medication disposal after death

IDAHO | WENY TV News (Horseheads, State of New York) – 29 May 2018 – Although many Idahoans struggle with opioid addiction, prescription painkillers play a major role in health care at the end of life. When patients enter hospice care, opioids are key to providing comfort in their final days and weeks, but hospice employees are faced with a difficult situation after the patient passes. In 2014, the Drug Enforcement agency changed the rules around hospice, saying at the time of a patient's death hospice employees are no longer able to dispose of leftover medications. Legislation circulating on Capitol Hill could change that. https://goo.gl/f6R6Qv

Too many Americans fail to plan for end-of-life care

STATE OF WASHINGTON | The Seattle Times - 28 May 2018 - We as a society have not come to terms with dying as a natural part of living. The technological capabilities of medicine have outstripped the moral capacity to distinguish what can be done versus what should be done. This results in end-of-life (EoLC) care that is often aggressive, expensive and not aligned with patient preferences. Far too many of us die in hospitals, in pain, isolated from their friends and families. These statistics make clear the scope of our problem: 1) Although 90% of those on Medicare say they want EoLC at home. only one-third achieve it; 2) 25% of all Medicare spending is for patients who are in their final year of life, most of that money spent in their last couple of months for care which is often of little apparent benefit; 3) The default standard of care is "all necessary care." (This standard of heightened levels of care contributes to the estimated \$810 billion in unnecessary, unbeneficial, or wasteful care provided to Medicare beneficiaries who spend most of their Medicare dollars in the

last year of life.): 4) Despite overwhelming conformity when it comes to what Americans claim is important to them at the end of their life, patients do not always receive the level of care they desire. (Among those seniors who have taken the time to spell out for their physicians how they envision their final days, only 2% of respondents requested "all possible care."); and, 5) A study of patients who understood themselves to be terminally ill with advanced cancers found that only 17% of respondents expressed interest in "life extending treatment." (Instead, most patients valued quality of life over extending it.) <u>https://goo.gl/JdGc6k</u>

Specialist Publications

'Advance directives information delivery in Medicare/Medicaid-funded agencies: An exploratory study' (p.11), in *Journal of Social Work in End-of-Life* & Palliative Care.



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/SCHoAG

Doctors face scrutiny about defining death

THE WALL STREET JOURNAL | Online – 28 May 2018 – What is the definition of death – and who gets to make the call? For decades, physicians have had the authority to declare a person brain-dead – defined in the U.S. as the irreversible cessation of all brain function, including the brainstem – even if heart and lung activity can be maintained with machines. The medical profession determined the acceptable tests and procedures used to make the diagnosis. But lately, the declaration of brain death has come under intense scrutiny. More families are challenging the determination of brain death in loved ones, and a small number of high-profile cases have sparked debate on social media and prompted some doctors to publicly discuss their definition of death. In response to the public conversation around brain death, some doctors say they are encouraging patients' families to observe when tests are conducted that help determine brain death. Meanwhile, some of the legal cases, especially the high-profile case involving 17-year-old Jahi McMath, have the potential to lead to public reassessment of established legal and medical principles. https://goo.gl/w99x3W

N.B. Additional articles on the Jahi McMath case (and on other, similar cases) noted in the 14 May 2018 issue of Media Watch (#563, p.8).

Arizona ranks 31st out of 50 states in health, well-being of seniors in national report

ARIZONA | The Arizona Daily Star (Tucson) -27 May 2018 - The state dropped eight spots from last year, when it was ranked 23rd in America's Health Rankings Senior Report.¹ This year's report is based on the latest data from 2014 to 2017 that is compiled by state, federal and health agencies, along with national studies and surveys, said Dr. Rhonda Randall, senior adviser to the foundation. In ranking No. 1 in use of hospice care, Agnes C. Poore, Casa de la Luz Hospice co-founder and chief clinical officer, said in an email interview. "We know Arizona has a bigger population of older residents, so you could say our demographics for hospice care is right. But, more than that, I attribute the top ranking to a state-wide effort to educate the community - not only on hospice, but on the importance of making their wishes known for end-of-life (EoL) care. "As the report indicated, at EoL most people want to be in the comfort of their homes, surrounded by the people they love," Poore said. "Hospice makes that happen."

Poore said families are also becoming educated about Medicare hospice benefits... Arizona's success in educating families and caregivers about hospice care is the collaboration of socialservices agencies, medical professionals and community groups, including churches, that work and support older adults in their EoL journey, Poore said. <u>https://goo.gl/ztCF3R</u>

Extract from the United Health Foundation report

The percentage of hospice care and hospital deaths among chronically ill Medicare decedents have continuously improved since 2013. Since the first Senior Report in 2013, hospital deaths decreased 30% from 30.1% to 21% and hospice care increased 42% from 36.7% to 52% of chronically ill Medicare decedents aged 65 years and older.

N.B. Foundation's data on hospice: https://goo.gl/q52vga

1. '2018 Senior Report,' United Health Foundation, May 2018. Download/view at: <u>https://goo.gl/WxBfW5</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

GALLUP | Online – 31 May 2018 – 'Americans' strong support for euthanasia persists.' A broad majority of Americans, 72%, continue to believe that doctors should be legally allowed, at a patient's and a family's request, to end a terminally ill patient's life using painless means. While support for legalized euthanasia is strong across nearly all subgroups of Americans, men, young adults, Democrats and liberals are especially likely to favor it. Support drops below a majority only among weekly church-goers. Since 1990, American support for the practice hasn't dipped below 64% and has been as high as 75% https://goo.gl/jynLSN

International

Bereaved parents "let down at work by lack of support"

U.K. | BBC News - 1 June 2018 - Two out of five parents who went back to work after their baby died said no-one talked to them about their loss, a charity says. A survey of more than 2,500 bereaved parents also found most employers did not offer any support. Sands, the stillbirth and neonatal death charity, is calling on colleagues and employers to find the words to talk about the loss of a baby. Responses to the survey found that only one in five parents had been offered or given any support by their employer on their return to work and around half said employers did not discuss entitlements to pay and leave following the death of their baby. Two out of five parents said they were not offered any additional time away from work. If a baby is stillborn after 24 weeks pregnancy, or is born alive at any time but dies shortly after birth, parents are entitled to maternity, paternity and shared parental leave, as well as full parental rights and benefits. In the U.K. every day, 15 babies die before, during or soon after birth. https://goo.gl/UJnD99

Specialist Publications

'Exploring the relationship between volunteering and hospice sustainability in the U.K.: A theoretical model' (p.9), in *International Journal of Palliative Nursing.*

'Representing whom? U.K. health consumer and patients' organizations in the policy process' (p.10), in *Journal of Bioethical Inquiry*.

'Palliative curriculum re-imagined: A critical evaluation of the U.K. palliative medicine syllabus' (p.11), in *Palliative Care: Research & Treatment*.

'Patient safety in palliative care: A mixed-methods study of reports to a national database of serious incidents [in England]' (p.12), in *Palliative Medicine*.

'Physician-assisted suicide and euthanasia: Emerging issues from a global perspective' (p.15), in *Journal of Palliative Care.*

Noted in Media Watch 22 December 2014 (#389, p.16):

- BEREAVEMENT CARE, 2014;33(3):111-112. 'Handling bereavement in the workplace a guide for employers.' The authors discuss the recently published Advisory, Conciliation & Arbitration Service guidance for employers on handling bereavement in the workplace.¹ Abstract (w. link to references): http://goo.gl/vpNuEw
 - 'Managing bereavement in the workplace: A good practice guide,' Advisory, Conciliation & Arbitration Service, 2014. [Noted in the 22 September 2014 issue of Media Watch (#376, p.15)] Download/view at: <u>https://goo.gl/9vcbaX</u>

70% of key hospitals in Japan halted, avoided life-prolonging care for some terminal patients: Poll

JAPAN / *The Mainchi Shimbun* (Tokyo) – 31 May 2018 – About 70% of key emergency hospitals that replied to a *Mainichi Shimbun* survey discontinued or decided not to provide life-prolonging treatment for some of their terminally ill patients last year. The survey sheds light on the difficult decisions medical institutions face amid the ballooning numbers of the elderly in Japanese society over whether to try to prolong the lives of patients who have no prospects of recovering. A total of 308 patients died after their life-prolonging treatment was aborted and 812 passed away because institutions decided not to provide such treatment... In a question about the reason for discontinuing or deciding not to provide life-prolonging treatment in which multiple answers were permitted, an overwhelming majority – 89% – cited the desire of the patients' illnesses on their families. With regard to how the medical institutions confirmed the patients' or their families' will, 80% answered that the patients' families made the decision or the families assumed the patients' will. Only 20% replied that the institutions confirmed their decisions with the patients them-selves. https://goo.gl/d5rbZP

We spend generously to extend lives of people with terminal illnesses – against the public's wishes

U.K. (England, Scotland & Wales) | *The Conversation* – 31 May 2018 – When deciding which treatments publicly funded healthcare systems should provide, medicines that extend terminally ill patients' lives are among the most hotly debated – particularly for advanced cancer. The National Health Service spent an estimated £17 billion on medicines in England in 2016-2017, roughly 13% of its budget. This was up from £13 billion in 2010-2011, with the medicine bill currently increasing at over 5% a year as new drugs get ever more expensive. Underlying this is a controversy many people probably aren't aware of. The relevant authorities – the National Institute for Health & Care Excellence in England & Wales, and the Scottish Medicines Consortium – take a more generous approach to approving end of life (EoL) drugs than all other drugs. Yet according to research, most people are not in favour. Previous studies show mixed results on public values in this context...^{1,2} https://goo.gl/o1HvDR

- 'Valuing health at the end of life: A review of stated reference studies in the social sciences literature,' Social Science & Medicine, 2018;204(5):39-50. [Noted in the 26 March 2018 issue of Media Watch (#556, p.16)] Abstract: <u>https://goo.gl/QFL9E9</u>
- 'Are life-extending treatments for terminal illnesses a special case? Exploring choices and societal viewpoints,' *Social Science & Medicine*, 2018;198(2):61-69. [Noted in the 1 January 2018 issue of Media Watch (#544, p.24)] Full text: https://goo.gl/PDqBjh

Vatican hospital issues new charter on rights of "incurable" children

CATHOLIC NEWS AGENCY (Vatican City) | Online – 29 May 2018 – A month after the death of U.K. toddler Alfie Evans, the Vatican's Bambino Gesù children's hospital issued a new charter on the "rights of the incurable child" outlining basic rights for both parents and children.¹ The charter says children with terminal diseases have the right to second opinions and better diagnostic and palliative care (PC), as well as the right to better experimental treatments and to be moved across international borders. Consisting of 10 articles, the hospital's new charter draws on previous national and international charters for the rights of hospitalized children, and affirms that proper medical care does not involve just looking for a cure, but also includes PC, as well as spiritual and psychological support for the family. <u>https://goo.gl/KPZzJV</u>

1. 'Carta dei Diritti del bambino Inguaribile,' Bambino Gesù Ospedale Pediatrico, May 2018. **Download**/ view Italian language version at: <u>https://goo.gl/AQNYUV</u>

Ministry drafts regulations to implement Taiwan's patient autonomy act

TAIWAN | Focus Taiwan News Channel (Taipei) – 27 May 2018 – The Ministry of Health & Welfare has drafted regulations for the implementation of a new law that stipulates respect for patient autonomy in healthcare, including clear definitions of patient rights to the termination of life-sustaining treatments, as well as artificial nutrition and hydration. The draft regulations ... were prepared for the implementation of the new Patient Right to Autonomy Act, which is set to become effective in January 2019. Under the act, which was touted as the first of its kind in Asia, patients in five clinical conditions who have made an advance decision in healthcare, may have medical institutions or physicians partially or fully terminate, with-draw, or withhold life-sustaining treatments, artificial nutrition and hydration in accordance with the advance decision. https://goo.gl/vrr8bE

N.B. Additional articles on palliative and end-of-life care in Taiwan noted in the 8 January 2018 issue of Media Watch (#545, p.13).



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.

Australian Medical Association of Queensland calls for death classes in schools

AUSTRALIA (Queensland) | Education HQ (Melbourne, Victoria) – 25 May 2018 – Schools should be teaching children about ageing and death so they can better cope with the loss of loved ones and their own mortality, the Australian Medical Association of Queensland says. Adolescents should also be writing advanced care plans so that if they suffer a debilitating or life-threatening accident or illness, families and doctors can understand their wishes. Australia's ageing population meant younger people also needed a better understanding of their older relatives' end-of-life care options. Topics such as how to make a will could be folded into existing subjects, including legal studies, science and

Noted in Media Watch 10 April 2017 (#507, p.16):

health. Palliative Care Queensland has backed the proposal. <u>https://goo.gl/TpZ1GH</u>

Extract from Education HQ article

Learning about ageing and the process of dying in an educational forum would also prevent young people from adopting their parents' anxieties and concerns about the issue. In many families, death is a bit of a taboo topic that only gets discussed at crisis points. Death education at school would help remove any stigma. Dr. Richard Kidd, Australian Medical Association Queensland.

 PASTORAL CARE IN EDUCATION | Online – 28 March 2017 – 'Making death, compassion and partnership "part of life" in school communities.' Death can be considered a social taboo, a common source of fear and public avoidance. School communities are not immune to this, as the topic of death is constantly avoided. It is vital to understand how we can socially and culturally cultivate a positive regard for death, dying and bereavement in our school communities. Community members need to discuss these difficult issues and use strategies to enhance compassion, connectedness and support. Abstract (w. link to references): https://goo.gl/V4H7NR

Selected articles on including the topic of dying and death into the school curriculum

- U.S. (California) | NPR News 25 February 2017 'Doctor takes death education to high school classrooms.' [Noted in 27 February 2017 issue of Media Watch (#501, p.1) <u>https://goo.gl/496EbZ</u>
- U.S. (Hawaii) | KITV 4 News 10 February 2015 'lolani School offers hospice course to students.' [Noted in 23 February 2015 issue of Media Watch (#398, p.4)] <u>https://goo.gl/9n6Khe</u>
- U.S. (Minnesota) | International Falls Daily Journal 29 October 2011 'Students participate in endof-life simulation.' [Noted in 31 October 2011 issue of Media Watch (#225, p.3)] <u>http://goo.gl/cr7w5K</u>
- THE NETHERLANDS | The Age 14 February 2007 'Lesson in life and death: Pupils build dying teacher's coffin.' [Noted in 8 August 2011 issue of Media Watch (#213, p.9)] <u>http://goo.gl/6R3Tl1</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

AUSTRALIA (Australian Capital Territory) | *The Sydney Morning Herald* (Pyrmont, New South Wales) – 30 May 2018 – 'How your religion changes your views on the right to die.' Rank-and-file Christians are at odds with religious leaders on euthanasia, with some denominations more supportive of voluntary assisted dying than others. As an Australian Capital Territory (ACT) parliamentary inquiry into the end-of-life choices available to Canberrans continues, a survey of 1,004 people has revealed how nearly half (48%) of people with religious beliefs supported assisted dying laws. One of the report's authors, Anthony Hogan – who is an adjunct research professor with the Australian Centre for Christianity & Culture – said the findings supported the idea that some formal theological positions do not reflect the "views of the pews." While only 1% of respondents were from the ACT, Professor Hogan said the findings brought into question the extent church leaders could speak on behalf of their communities on public policy. https://goo.gl/RvPGCr

PORTUGAL | Reuters (Lisbon) – 29 May 2018 – 'Portugal's parliament rejects euthanasia, doctorassisted suicide.' A proposal to make Portugal one of only a handful of countries allowing euthanasia and doctor-assisted suicide was rejected by lawmakers. After a landmark debate, lawmakers voted to reject four broadly similar bills introduced by left-leaning parties. The bill that came closest to succeeding was the work of the governing Socialist Party, which failed on a 115-110 vote with four abstentions. The country's two main parties, the Socialists and the main opposition Social Democratic Party, allowed their lawmakers to vote according to their conscience. Euthanasia was forced onto the political agenda by a public petition urging its introduction in 2016. https://goo.gl/V2FTZs

Specialist Publications

Filling the gap: Creating an outpatient palliative care program in your institution

ASCO EDUCATIONAL BOOK, 2018:38(1):111-121. Despite the strong evidence of benefit and American Society of Clinical Oncology recommendations.¹ implementation of outpatient palliative care (PC), especially in community oncology settings, faces considerable hurdles. This article, based on published literature and expert opinion, presents practical strategies to help oncologists make a strong clinical and fiscal case for outpatient PC. The authors outline key considerations for how to build an outpatient PC program in an institution by: 1) Defining the scope and benefits; 2) Identifying strategies to overcome common barriers to integration of outpatient PC into cancer care; 3) Outlining a business case; 4) Describing successful models of outpatient PC; and, 5) Examining important factors in design and operation of a PC clinic. The advantages and disadvantages of different de-

livery models (e.g., embedded vs. independent) and different methods of referral (triggered vs. physician discretion) are reviewed. Strategies to make the case for outpatient PC that align with institutional values and/or are supported by local institutional data on cost savings are included. **Abstract:** <u>https://goo.gl/ayaZj7</u>

Journal Watch

'Predatory journals exploit structural weaknesses in scholarly publishing' (p.16), in 4Open.

'Introducing PALETTE: An iterative method for conducting a literature search for a review in palliative care' (p.16), in *BMC Palliative Care*.

'Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline update,' *Journal of Clinical Oncology*, 2017;35(1):96-112. [Noted in 31 October 2016 issue of Media Watch (#486, p.7)] Full text: https://goo.gl/RGjFMP

"How much time do I have?": Communicating prognosis in the era of exceptional responders

ASCO EDUCATIONAL BOOK, 2018;38(1):787-794. A robust literature shows that many patients with advanced cancer have inaccurate perceptions of their prognosis, thus raising questions about whether patients are truly making informed decisions. Clinicians' ability to communicate prognostic information is further complicated today by the availability of novel, efficacious immunotherapies and genome-guided treatments. Currently, clinicians lack tools to predict which patients with advanced disease will achieve an exceptional response to these new therapies. This increased prognostic uncertainty on the part of clinicians further complicates prognostic communication with patients. Evidence also suggests that many on-cologists avoid or rarely engage in prognosis-related communication and/or lack skills in this area. Although communication skills training interventions can have a positive impact on complex communication skills for some clinicians, there is no one-size-fits-all approach to improving patient-clinician communication about prognosis is linked with end-of-life care outcomes. Solutions to this problem will likely require a combination of interventions beyond communication skills training programs, including enhanced use of other cancer clinicians, such as oncology nurses and social workers, increased use of palliative care specialists, and organizational support to facilitate advance care planning. **Abstract:** https://goo.gl/ngWsDh

Language barriers restricting access to health care for Indigenous populations [in Canada]

CANADIAN MEDICAL ASSOCIATION JOURNAL | Online – 30 may 2018 – The lack of health services offered in Indigenous languages is impeding the delivery of care to Indigenous populations, according to Aluki Kotierk, president of Nunavut Tunngavik Incorporated, which administers



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treaty rights for the 49,000 Inuit inhabitants of Nunavut. The first language of 75% of the Inuit population in Nunavut is Inuktituk, yet patients are unlikely to hear it spoken by health care providers. "Many Inuit have little faith in the health system," Kotierk said at the [recent] Indigenous Health Conference. The gaps in Nunavut's health system can only be addressed by training local, Inuktituk-speaking health professionals, said Kotierk. With only one doctor for every 3,000 residents and almost two thirds of nursing positions vacant, the traditional reliance on professionals from outside the territory has proven inadequate. In many cases, she noted, health care workers who don't speak Inuktituk rely on patients and other staff as informal translators, although they have limited understanding of medical terminology. Training health care workers who speak local languages can reduce linguistic barriers to receiving adequate health care. A 2015 report by the Office of the Languages Commissioner of Nunavut found that language barriers have a negative impact on access to health care, patient confidentiality, access to mental health services, compliance to treatment plans and health care costs.¹ It also affects quality of care, and can lead to misdiagnoses, medical errors and improper medication, states the report. **Full text:** https://goo.gl/JCQ6mG

1. 'If You Cannot Communicate With Your Patient, Your Patient Is Not Safe,' Final Report of the Office of the Languages Commissioner, October 2015. Link to report via CBC website: <u>https://goo.gl/UmZYbh</u>

N.B. Selected articles on palliative and end-of-life care for the Indigenous peoples of Canada noted in the 14 May 2018 issue of Media Watch (#562, pp.10-11).

Exploring the quality of the dying and death experience in the Emergency Department: An integrative literature review

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 23 May 2018 – Sixteen articles are included. Eight themes emerged: 1) Care in the Emergency Department (ED) is about living not dying; 2) Staff perceive that death is a failure; 3) Staff feel underprepared to care for the dying patient and family in this environment; 4) There is limited time for safe standards of care; 5) Staff stress and distress; 6) Staff use of distancing behaviours; 7) The care of the dying role is devolved from medics to nurses at the end of life (EoL); and, 8) Patients and staff perceive that the ED is not the preferred place of death. There are areas of concern about EoL in the ED. To improve practice and to ensure that a good death occurs, further research is needed. There is a need to understand more about the experience of caregivers when a relative or friend dies in the ED. **Abstract (w. link to references):** https://goo.gl/5dwLLz

Exploring the relationship between volunteering and hospice sustainability in the U.K.: A theoretical model

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2018;24(5):212-219. A narrative literature review was conducted. A total of 90 documents were analysed. Emerging themes included the importance of volunteering to the hospice economy and workforce, the quality of services, and public and community support. Findings suggest that hospice sustainability is dependent on volunteers; however, the supply and retention of volunteers is affected by internal and external factors. A theoretical model was developed to illustrate the relationship between volunteering and hospice sustainability. It demonstrates the factors necessary for hospice sustainability and the reciprocal impact that these factors and volunteering have on each other. The model has a practical application as an assessment framework and strategic planning tool. **Abstract (w. link to references):** https://goo.gl/fvZkkV

N.B. Additional articles on the role of volunteers in hospice and palliative care noted in the 21 May 2018 issue of Media Watch (#564, p.12).

The evidence of early specialist palliative care on patient and caregiver outcomes

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2018;24(5):230-237. Although there are many differences regarding what palliative care (PC) is and to whom it should be delivered, its delivery and integration earlier in the disease trajectory have been advocated since 1990. More recently, there has been a heightened interest in early access to specialist PC through its provision earlier in the disease trajectory to improve patient and caregiver outcomes. This article explores the challenges in understanding and defining "early" specialist PC. It also examines the available evidence on early specialist PC interventions and their association with patient and caregiver outcomes. Finally, recommendations for future direction of research and practice are discussed. **Abstract (w. link to references):** https://goo.gl/w3N1aA

Is blogging a new form of communication in palliative health care? A qualitative research study

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2018;24(5):238-245. The aim of this study was to illuminate experiences of living with life-threatening diseases as described in blogs and the experience of blogging about these matters. A secondary analysis of 21 blogs was performed. It was difficult for bloggers to accept what they perceived to be the unacceptable aspects of having an life-threatening disease. They searched for hope and acceptance, and tried to manage their life. They felt strengthened by supportive encounters with health professionals, relatives, friends, and from their blogging. However, they also felt that they were set aside in relation to both health professionals and relatives. These patients appreciated being able to express their feelings and received support from their readers. Even if patient blogs can be used in health care, research and education, there is a lack of research studies that have examined the benefits of using blogging for any of these purposes. **Abstract (w. link to references):** https://goo.gl/LqSRLX

Representing whom? U.K. health consumer and patients' organizations in the policy process

JOURNAL OF BIOETHICAL INQUIRY | Online – 25 May 2018 – This paper draws on nearly two decades of research on health consumer and patients' organizations (HCPOs) in the U.K.. In particular, it addresses questions of representation and legitimacy in the health policy process. HCPOs claim to represent the collective interests of patients and others such as relatives and carers. At times they also make claims to represent the wider public interest. The authors explore how and in what sense HCPOs represent their constituencies. They found that policymakers themselves are less concerned with formal mechanisms adopted by groups and are more concerned with credibility, in particular whether HCPOs carry the confidence of their constituents. While some concerns about legitimacy remain, particularly in relation to funding from commercial interests, the authors argue that HCPOs bring a unique perspective to the policy process and to focus purely on formalistic representation provides only a partial understanding of their representative role and a constrained view of their collective moral claims. **Abstract (inc. list of references):** https://goo.gl/dCqqtS

The spiritual event of serious illness

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 29 May 2018 – Thought leaders in palliative care have long recognized the spiritual implications of illness, including Dame Cicely Saunders' groundbreaking concept of suffering as comprised of physical, emotional, social, and spiritual sources of pain. However despite such recognition, spirituality remains an oft-neglected component of the biopsychosocial spiritual model of caregiving in serious illness. The authors highlight, through an in depth account of patients' experiences and attitudes, the concept of illness as a "spiritual event." Abstract (w. link to references): https://goo.gl/nR43Lz



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

Palliative care in the U.S.

Palliative care use among patients with solid cancer tumors: A National Cancer Data Base study

JOURNAL OF PALLIATIVE CARE | Online – 29 May 2018 – There is a current gap in knowledge regarding why palliative care (PC) is underutilized nationwide. Using the 2016 National Cancer Data Base, the authors identified deceased patients (2004-2013) with breast, colon, lung, melanoma, and prostate cancer. Associations between PC use and patient, facility, and geographic characteristics were evaluated through multivariate logistic regression. A total of 1,840,111 patients were analyzed; 9.6% received PC. Patients who lived in communities with a greater percentage of high school degrees had higher odds of receiving PC; Central and Pacific regions of the U.S. had lower odds of PC use than the East Coast. Patients with colon, melanoma, or prostate cancer had lower odds of PC than patients with breast cancer, whereas those with lung cancer had higher odds. **Abstract:** https://goo.gl/8CFmgn

U.S. Medicare/Medicaid

Advance directives information delivery in Medicare/ Medicaid-funded agencies: An exploratory study

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 29 May 2018 – Under the Patient Self-Determination Act, all Medicare/Medicaid-funded agencies are required to ask if all the patients, upon admission, have advance directives (ADs). If they have not formulated an AD, agencies need to inform that they have a right to do so and provide them with the written information. Although this is required by law, there is no universal procedure or set standard approach to deliver the information to patients in these agencies. It is often unclear who provides and explains information on ADs, and what materials are provided. Using a case study approach, semi-structured interviews with personnel in nine agencies were analyzed and three overarching themes were identified: 1) Organizational procedures; 2) Staff interactions; and, 3) Staff perceptions. The findings indicated that there is a need for AD-specific training for staff responsible for delivering AD information to their clients. **Abstract:** https://goo.gl/BuR1Hr

Related

THE HASTINGS REPORT, 2018;43(3):8-9. 'Change without change? Assessing Medicare reimbursement for advance care planning.' In January 2016, Medicare began reimbursing clinicians for time spent engaging in advance care planning (ACP) with their patients or patients' surrogates. Although it seems that political barriers to reimbursement for such planning have largely faded, the Medicare policy's impact on provider billing practices appears to be limited, suggesting other barriers to clinician engagement in ACP. Additionally, the effects of this policy on patient behavior and the clinician-patient relationship are not yet known. Abstract: https://goo.gl/nh8roF

Palliative curriculum re-imagined: A critical evaluation of the U.K. Palliative Medicine syllabus

PALLIATIVE CARE: RESEARCH & TREATMENT | Online – 28 May 2018 – The curriculum for U.K. Palliative Medicine will inevitably undergo revision. When that time and process comes around again, the authors suggest that the public health (PH) approach to palliative care (PC) is embedded in the new curriculum. Medical colleagues from PH and geriatric medicine are crucial for a more informed PH framework and a more balanced understanding of both the epidemiology of ageing and dying as well as caregiving and bereavement. The omission of discussion and learning objectives related specifically to aged care is deeply unfortunate for a PC training document. PC is not solely terminal cancer care. The clinical and policy demands for a broader involvement in ageing-related disease such as neurological disorders, organ failure, dementia, and even frailty have been debated and argued for over a decade now. The exponential rise in demographic ageing trends makes this attention even more urgent. Collaboration with gerontology can only strengthen the relevance and value of future PC learning and practice. Second, it will

be important to consult the established academic literature on health-promoting PC and to closely examine the existing PC policy documents for their stipulations and recommendations for social forms of support and care. Leadership and partnership are crucial new roles for palliative medicine in an age of the "new" PH. Psychosocial approaches to care affirm the dominant direct service culture of palliative medicine and fail to direct attention to the crucial partnership challenges of working with community. These limits to psychosocial care are invitations to a greater understanding of health promotion and community development. Finally, PH insights must be applied understandings for PC and not solely abstract epidemiological information bereft of practice guidance. **Full text:** https://goo.gl/jeC4Qd

Noted in Media Watch 13 June 2016 (#466, p.14):

PROGRESS IN PALLIATIVE CARE | Online – 9 June 2016 – 'Which public health approach to palliative care? An integrative literature review.' Public health (PH) and palliative care (PC) are both broad disciplines with blurred boundaries. There is growing support for an alignment of PC to PH. Given the novel nature of this alignment and the ambiguity of the parent definitions, there is an understandable lack of clarity around this merged model. The aim of this study is to describe the theoretical features of the PH approach to PC as articulated in the current research literature. Abstract (w. link to list of references): http://goo.gl/4EGYB0

N.B. Additional articles on a public health approach to end-of-life care noted in this issue of Media Watch.

Patient safety in palliative care: A mixed-methods study of reports to a national database of serious incidents [in England]

PALLIATIVE MEDICINE | Online – 1 June 2018 – Patients receiving palliative care (PC) are vulnerable to patient safety incidents, but little is known about the extent of harm caused or the origins of unsafe care in this population. A total of 475 reports [to a national database of "serious incidents requiring investigation" involving patients receiving PC in the National Health Service in England during the 12-year period, April 2002 to March 2014] were identified: 266 related to pressure ulcers, 91 to medication errors, 46 to falls, 21 to healthcare-associated infections, 18 were other instances of disturbed dying, 14 were allegations against health professions, 8 transfer incidents, 6 suicides and 5 other concerns. The frequency of report types differed according to the care setting. Underlying causes included lack of PC experience, under resourcing and poor service coordination. Resultant harms included worsened symptoms, disrupted dying, serious injury and hastened death. Unsafe care presents a risk of significant harm to patients receiving PC. Improvements in the coordination of care delivery alongside wider availability of specialist PC support may reduce this risk. **Abstract:** <u>https://goo.gl/3ygxTA</u>

N.B. Selected articles on medication errors in palliative care noted in the 14 May 2018 issue of Media Watch (#563, p.11). additional articles on patient safety noted in the 15 August 2016 issue of the weekly report (#475, p.6)]



13 October 2018

https://goo.gl/sxz85U

Voices for hospices



http://goo.gl/OTpc8l

Researching children's perspectives in pediatric palliative care: A systematic review and meta-summary of qualitative research

PALLIATIVE & SUPPORTIVE CARE | Online -29 May 2018 – Qualitative research is pivotal in gaining understanding of individuals' experiences in pediatric palliative care (PC). In the past few decades, the number of qualitative studies on pediatric PC has increased slightly, as has interest in qualitative research in this area. Nonetheless, a limited number of such studies have included the first-person perspective of children. The aim of this article is to understand the contribution of previous qualitative research on pediatric PC that included the voices of children. A systematic review of qualitative studies and a meta-summary were conducted. The authors retrieved 16 qualitative research articles reporting on 12 unique studies, and they selected two mixed-method articles. The meta-summary shows eight themes: 1) The relationship with professional caregivers; 2) Pain and its management; 3) "Living beyond pain," 4) The relationship between pediatric patients and their families; 5) Children's view on their treatment and service provision; 6) Meanings children give to their end-of-life situation; 7) Consequences of clinical decisions; and, 8) The rela-

Noted in Media Watch 30 April 2018 (#561, p.8):

tionships among children in pediatric PC and their peers. This meta-summary presents the "state of the art" of pediatric PC qualitative research on children and highlights additional research areas that warrant qualitative study. **Abstract:** https://goo.gl/2jPNKP



BEHAVIORAL SCIENCES | Online – 26 April 2018 – 'Ethics of end-of-life decisions in pediatrics: A narrative review of the roles of caregivers, shared decision-making, and patient centered values.' While a paternalistic approach is typically applied to children with life-limiting medical prognoses, the cognitive, language, and physical variability in this patient population is wide and worthy of review. In end-of-life (EoL) discussions in pediatrics, the consideration of a child's input is often not reviewed in depth, although a shared decision-making model is ideal for use, even for children with presumed limitations due to age. Full text: https://goo.gl/Py1bVH

End-of-life decision making by family caregivers of persons with advanced dementia: A literature review of decision aids

SAGE OPEN MEDICINE | Online – 21 May 2018 – Few decision aids exist for caregivers' end of life (EoL) decision making for persons with dementia. Existing studies lacked a focus on caregivers' preferences for different types and amounts of information necessary to ensure decision making consistent with patients' values. Advance care planning (ACP) for persons with dementia is a major challenge for caregivers. Ideally, the demands of an advance directive or any kind of ACP would have been discussed with the person with dementia while he or she was still able to express such wishes. Yet, this is often not the case. Developers of decision aids should strive to find ways to incorporate values and preferences in decision making. None of the studies[reviewed] mentioned any tailoring or acknowledged the need for specific tailoring of information to the individual situations of patients or caregivers. Important variables for tailoring such as values and information preferences were typically not assessed before or during the implementation of decision aids. While recent technological developments enable great tailoring of informa-

tion, existing decision aids have largely underutilized such tailoring potential. Existing studies involved samples predominantly of non-Hispanic Caucasians. Since EoL decision making is culturally sensitive, future research should place special emphasis on ethnically and racially diverse samples and develop tailored and interactive decision aids for underrepresented groups. **Full text:** <u>https://goo.gl/jFnZQz</u>

Noted in Media Watch 9 April 2018 (#558, p.8):

 JOURNAL OF ADVANCE NURSING | Online – 30 March 2018 – 'The experiences and preparedness of family carers for best interest decision making of a relative living with advanced dementia: A qualitative study.' Three themes were identified: 1) Caring for someone living with dementia (the impact on the carer's holistic well-being and their experience of being a best interest decision-maker); 2) Accessing support (the influential nature of formal and informal networks); and, 3) Perceived knowledge and understanding of the dementia trajectory of carers and nursing staff. Abstract: https://goo.gl/8rMBBP

N.B. Additional articles on palliative and end-of-life care for people living with Alzheimer's and other forms of dementia noted in the 21 May 2018 issue of Media Watch (#564, p.8).

Assisted (or facilitated) death

Representative sample of recent journal articles:

- BMC MEDICAL ETHICS | Online 30 May 2018 'Changes in attitudes towards hastened death among Finnish physicians over the past sixteen years.' Considering a hypothetical case scenario, Finnish physicians [i.e., survey respondents] accepted the risk of hastening death more often in 2015 than in 1999. The specialty of the physician, gender, and faith in God strongly influenced their acceptance to this practice. Oncologists were the most reluctant of all the specialists studied to hasten death. Euthanasia, but not assisted suicide, was considered slightly less reprehensible in 2015. Relieving suffering, while considering the justification to hasten death, is a complex ethical question. Therefore, both training in medical ethics and medicine are needed for high quality end-of-life care. Full text: https://goo.gl/iMJHXn
- CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2018;27(3):366-375. 'A life fulfilled: Should there be assisted suicide for those who are done with living?' A large number of Dutch people feel that elderly people (i.e., people who have reached the age of 70) with a "fulfilled life" should have access to assisted suicide. Citizens have therefore requested Parliament to expand the existing legislation that governs euthanasia and physician-assisted suicide. The Dutch constitution does not permit national legislation to be incompatible with higher international (human rights) law. An analysis of the case law of the European Court of Human Rights shows that a person's right to decide on the time and manner of his or her death should be regarded as an aspect of the right to privacy. Although no positive obligation has been imposed on parties to the European Convention for the Protection of Human Rights & Fundamental Freedoms to facilitate suicide, they may do so, provided that certain conditions are met. Abstract (inc. list of references): https://goo.gl/KwGuhu
- CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 2018;27(3):376-384. 'Quality of living and dying: Pediatric palliative care and end-of-life decisions in The Netherlands.' An emerging major question regards the active ending of life in the context of palliative care (PC): How does a request for active ending of life relate to the care that is given to children in the palliative phase? Until now, the distinction between PC and end-of-life (EoL) decisions continues to remain unclear, making any discussion about their mutual in- and exclusiveness hazardous at best. The authors aim to provide insight into the relationship between pediatric PC and EoL decisions, as understood in The Netherlands. They do so by first providing an overview of the (legal) rules and regulations regarding euthanasia and active ending of life, followed by an analysis of the relationship between these two, using the Dutch National Guidelines for Palliative Care for Children. The results of this analysis revealed two major and related features of PC and EoL decisions for children: 1) PC and EoL decisions are part of the same process, one that focuses both on quality of living and quality of dying; and, 2) Although physicians are seen as ultimately responsible for making EoL decisions, the involvement of parents and children in this decision is of the utmost importance and should be regarded as such. Abstract (inc. list of references): https://goo.gl/qfksZm

- CLINICAL TRANSPLANTATION | Online 23 May 2018 'Organ donation after euthanasia, morally acceptable under strict procedural safeguards.' The authors present a case of organ donation after active euthanasia (ODE) in The Netherlands from a patient who had his life ended at his explicit and voluntary request. The form of ODE described concerns patients who are not unconscious and on life support, but who are conscious and want to have their life ended because of their hopeless and unbearable suffering, for instance due to a terminal illness such as amyotrophic lateral sclerosis or multiple sclerosis. This form of ODE is of course only possible in jurisdictions where euthanasia is allowed. In these jurisdictions, organ donation after euthanasia is an option that may be considered. The authors believe ODE is worthwhile to pursue, as it can strengthen patient autonomy, can give meaning to the inevitable death of the patient, and be an extra source of much needed donor organs. To ensure voluntariness of both euthanasia and organ donation and avoid conflict of interest by physicians, ODE does need strict procedural safeguards however. The most important safeguard is a strict separation between the two procedures. The authors discuss several ethical issues such as who should broach the subject of organ donation and who should perform the euthanasia, and how a conflict of interest can be avoided. Abstract: https://goo.gl/efSyGE
- JOURNAL OF PALLIATIVE CARE | Online 1 June 2018 'Physician-assisted suicide and euthanasia: Emerging issues from a global perspective.' Medical professional societies have traditionally opposed physician-assisted suicide and euthanasia (PAS-E), but this opposition may be shifting. The authors present 5 reasons why physicians shouldn't be involved in PAS-E: 1) Slippery slopes (There is evidence that safeguards in The Netherlands and Belgium are ineffective and violated, including administering lethal drugs without patient consent, absence of terminal illness, untreated psychiatric diagnoses, and non-reporting); 2) Lack of self-determination (Psychological and social motives characterize requests for PAS-E more than physical symptoms or rational choices; many requests disappear with improved symptom control and psychological support); 3) Inadequate palliative care (PC) (Better PC makes most patients physically comfortable. Many individuals requesting PAS-E don't want to die but to escape their suffering. Adequate treatment for depression and pain decreases the desire for death); 4) Medical professionalism (PAS-E transgresses the inviolable rule that physicians heal and palliate suffering but never intentionally inflict death); 5) Differences between means and ends (Proeuthanasia advocates look to the ends - the patient's death - and say the ends justify the means; opponents disagree and believe that killing patients to relieve suffering is different from allowing natural death and is not acceptable). Physicians have a duty to eliminate pain and suffering, not the person with the pain and suffering. Solutions for suffering lie in improving PC and social conditions and addressing the reasons for PAS-E requests. They should not include changing medical practice to allow PAS-E. Abstract: https://goo.gl/5BxJRY
- JOURNAL OF PSYCHIATRIC & MENTAL HEALTH NURSING | Online 26 May 2018 'The attitudes, role & knowledge of mental health nurses towards euthanasia because of unbearable mental suffering in Belgium: A pilot study.' Nurses do not appear to have a common voice on the topic and the development of clear guidelines appears to be essential. Social recovery can offer a way out of an UMS euthanasia request, but it will not always offer a solution. Sufficient attention must be paid to how mental health nurses can be involved in the process of unbearable mental suffering euthanasia at various levels: bedside practice, healthcare management, education and policy. A form of systematic cooperation between nurses, physicians and patients can contribute to the utmost careful decision-making process needed in these cases. There is a need for proper training in: knowledge of psychiatric pathologies and remaining treatment options; communication skills; the legal framework and all its difficulties; transdisciplinary and multicultural approaches; ethical reflection and how nurses handle their own emotions. Abstract: https://goo.gl/QJ5wUB
- THE NEW ENGLAND JOURNAL OF MEDICINE, 2018;378(22):2060-2062. 'Beyond legalization dilemmas physicians confront regarding aid in dying.' Because 18.2% of the U.S. population lives in jurisdictions where physician aid in dying (PAD) is now legal, physicians need to anticipate that patients may inquire about or request it. Two decades ago, when PAD was illegal throughout the U.S., 18.3% of physicians reported ever having received a request for assisted suicide; inquiries are likely to be more frequent now. But physicians may feel unprepared, uncertain, and uncomfortable when confronting these conversations, even if they've thought through their own position on PAD legalization. Physicians can start by clarifying what patients are asking and why. Some ways in which patients might raise the topic of PAD are listed... Not every question about PAD is a request for assisted suicide. Patients might be seeking information, talking through concerns, expressing distress, or trying to ascertain the physician's views. To clarify the patient's motivation, physicians might say, "I'll be glad to answer that question, but first please tell me what led you to ask." Full text: https://goo.gl/iuEjJx

Journal Watch

Predatory journals exploit structural weaknesses in scholarly publishing

40pen | Online - 1 June 2018 - The scholarly publishing process - from initial submission to final publication - has many weak points subject to exploitation. Some open-access publishers have taken advantage of these vulnerabilities, profiting by cheating scholarly authors and the consumers of research, the readers. The openaccess social movement has facilitated this exploitation, preferring to advance its ideology at the expense of good science. The result is that scholarly publishing is now operating in a crisis mode, with activist science and pseudo-science being presented as legitimate in scholarly literature. Academic evaluation is also suffering, with some researchers taking advantage of the easy acceptance the predatory publishers offer to quickly publish research articles, works that earn academic credit that lead to tenure and promotion and augment CVs shown to prospective employers. Before the advent of open-access journals, scholarly publishing was largely governed by a sustained implementation of the "gentlemen's agreement," which, according to Oxford English Dictionary Online is "an agreement which is not enforceable at law, and which is only binding as a matter of honour. With open-

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access journals, readers and libraries no longer have a say on which journals succeed or fail, an important quality-control function that's rapidly being lost. You cannot cancel a subscription to an open-access journal. Instead, the authors financing the publication of articles in openaccess journals exercise the economic clout to determine the winners. Increasingly, the winners are the journals selling quick and easy acceptance of submitted articles at low fees. **Full text:** https://goo.gl/BEb7sY

Extract from 40pen article

There's nothing inherently wrong with the openaccess publishing model, but to be successful, it must be managed properly, in a way that benefits science, those who carried out and reported the research, and the readers and other "consumers" of the research. Not all open-access journals are predatory, nor are all subscription journals of high quality. Any humanbased enterprise will prove imperfect over time.

BMC PALLIATIVE CARE | Online – 2 May 2018 – In the rapidly developing specialty of palliative care (PC), literature reviews have become increasingly important to inform and improve the field. When applying widely used methods for literature reviews developed for intervention studies onto PC, challenges are encountered such as the heterogeneity of PC in practice (wide range of domains in patient characteristics, stages of illness and stakeholders), the explorative character of review questions, and the poorly defined keywords and concepts. To overcome the challenges and to provide guidance for researchers to conduct a literature search for a review in PC, Palliative cAre Literature rEview iTeraTive mEthod (PALLETE), a pragmatic framework, was developed. The authors assessed PALETTE with a detailed description. By using PALETTE on two PC literature reviews, they were able to improve their review questions and search strategies. Moreover, in comparison with the recommended search for intervention reviews, the number of articles needed to be screened was decreased whereas more relevant articles were retrieved. PALETTE helped gain a thorough understanding of the topic of interest and made the authors confident the included studies comprehensively represented the topic. **Full text:** https://goo.gl/fKiF7N



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

Media Watch: Editorial Practice

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Barry R. Ashpole Guelph, Ontario CANADA phone: 519.837.8936) e-mail: <u>barryashpole@bell.net</u>