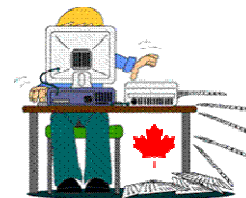


Media Watch...

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

Meeting the challenge of “the unknown”: Scroll down to [Specialist Publications](#) and ‘Health care professionals’ understandings of cross-cultural interaction in end-of-life care: A focus group study’ (p.12), in *Plos One*.

Canada

Fighting for the “right to try”: Terminally ill Canadians want legal right to access unproven treatments

THE NATIONAL POST | Online – 2 December 2016 – About a month ago, a group of people with terminal illnesses wrote to members of Parliament, asking for legislation that would give the dying the right to access unapproved drugs and treatments. “I’m going to die anyway,” said right-to-try campaign co-founder Jeff Perreault, who has ALS, also known as Lou Gehrig’s disease. While competent people facing a foreseeable death have the legal “right to die” in Canada, they don’t have the “right to try” something that might prolong their lives, he says. “We have the law that allows us to kill ourselves. We just don’t have the law to do something else.” After a meeting with Perreault recently, Health Minister Jane Philpott said officials were studying the issue and would determine what actions were required. It’s not unfathomable that right to try will come to Canada, said Timothy Caulfield, the Canada Research Chair in Health Law & Policy and a professor in law and public health at the University of Alberta. That said, it’s not a step he would welcome. What he finds most concerning is that right-to-try campaigns are based on the belief regulators are withholding useful therapies. <https://goo.gl/InDMSi>

Noted in Media Watch 7 November 201, #486 (p.1):

- *THE OTTAWA CITIZEN* | Online – 3 November 2016 – ‘**Terminally ill patients campaign for “right-to-try” treatments.**’ A group of patients with terminal illnesses is urging MPs to give them the “right-to-try” unapproved treatments. There are 28 members of the group, all with amyotrophic lateral sclerosis (ALS) or terminal cancer... According to the group’s proposal, patients who are eligible for the “right-to-try” would need to have a terminal illness and have tried all other treatment options already approved by Health Canada. Health Canada’s special access program allows doctors access to drugs and medical devices that have not yet been approved for sale in Canada to treat patients with serious or life-threatening conditions when conventional therapies have failed, or if they are unsuitable or unavailable. <https://goo.gl/IKKRNg>

N.B. Additional articles on the “right-to-try” laws are noted in this issue of Media Watch.

Shadowy publisher of Canadian medical journals retracts “steaming pile of dung”

THE OTTAWA CITIZEN | Online – 28 November 2016 – Last week, the *Citizen* exposed scientific fraud by the new owners of two Canadian medical publishing firms – printing fake research for cash. Now, after the news got international publicity, the company that published our trashy little fake study is retracting it. Here’s the back story: OMICS International, based in India, bought Pulsus Group and Andrew John Publishing this year. Both were reputable medical journal publishers, but under OMICS they have been used as fronts for “predatory” publishing. This is the practice of publishing fake or incompetent research for cash, because it makes unqualified

authors look legitimate. Predators are a growing problem in scientific literature, blurring what’s real research and what isn’t. We asked OMICS last week why it had published the plagiarized and meaningless paper we sent them as a test. We asked OMICS ... why it had published the plagiarized and meaningless paper we sent them as a test. <https://goo.gl/9n3Col>

The OMICS Group of publications include the *Journal of Palliative Care & Medicine*: <http://goo.gl/ieTbLZ>.

Noted in Media Watch 3 October 2016, #482 (p.1):

- CTV NEWS | Online – 29 September 2016 – ‘**Offshore firm accused of publishing junk science takes over Canadian journals.**’ An offshore publishing company accused of disseminating junk science and duping researchers has taken over the publishing of several respected Canadian medical journals, a joint CTV News/*Toronto Star* investigation has found. <https://goo.gl/yLi42q>

N.B. See also Retraction Watch: <https://goo.gl/xnL5G8>. Additional articles on predatory journals are noted in Media Watch 5 September 2016, #478 (p.14), 30 May 2016, #464 (p.11), 11 April 2016, #457 (p.7), 29 February 2016, #451 (p.9), and 8 February 2016, #448 (p.9).

U.S.A.

Talks with families tied to fewer hospitalizations from nursing homes



CONNECTICUT | Reuters – 29 November 2016 – Nursing homes that send fewer residents to the hospital at the end of life (EOL) might do a better job of communicating with families about the pitfalls of aggressive interventions than other facilities, a recent U.S. study suggests.¹ At the EOL, hospital stays for seriously injured or ill nursing home residents typically offer little hope of improving quality of life or changing outcomes for the better, researchers noted... “We found that nursing home staff at all facilities encountered the same barriers to avoiding potentially burdensome hospitalizations, but that staff at low-hospitalizing facilities did two things very differently from those at high-hospitalizing ones,” said lead study author Dr. Andrew Cohen of Yale University in New Haven, Connecticut. “They avoided decision-making algorithms and did not send patients to the hospital by default when an acute event occurred,

and they viewed it as their role to try to change families’ minds when they requested a hospitalization that was unlikely to be beneficial,” Cohen added by email. While previous research has found hospitalization rates generally tend to be lower at non-profit nursing homes or at places with well-used hospice programs, less is known about what factors might influence the odds of hospital stays at the EOL at individual facilities, Cohen said. <https://goo.gl/mL7j9Q>

Specialist Publications

‘Goals of care or goals of trust? How family members perceive goals for dying nursing home residents’ (p.9), in *Journal of Palliative Medicine*.

‘Events leading to hospital-related disenrollment of home hospice patients: A study of primary caregivers’ perspectives’ (p.11), in *Journal of Palliative Medicine*.

Cont.

1. 'Avoiding hospitalizations from nursing homes for potentially burdensome care: Results of a qualitative study,' *JAMA Internal Medicine*, 28 November 2018. <https://goo.gl/M3lzDh>

What not to say to a cancer patient

THE NEW YORK TIMES | Online – 28 November 2016 – A diagnosis of cancer can tie the tongues of friends and family members or prompt them to utter inappropriate, albeit well-meaning, comments. Some who don't know what to say simply avoid the cancer patient altogether, an act that can be more painful than if they said or did the wrong thing. <https://goo.gl/P6YiqR>

Respect the wishes of aging patients: Few efforts to assess health care quality focus on what patients want near the end of life

U.S. NEWS & WORLD REPORT | OpEd – 28 November 2016 – The U.S. health care system lacks the ability to measure whether patients and families are receiving high-quality care near the end of life (EOL) that reflects their goals and preferences. As a result, the health care system often fails to provide individuals and families – when they are at their most vulnerable – with what experts call patient-centered care. For example, although the majority of people say they would prefer to die at home, today two-thirds of seniors die elsewhere, such as hospital intensive care units or nursing homes, where they may receive unwanted treatment. This failure to honor people's wishes near the EOL is likely to grow as the population ages. The number of people in the U.S. 65 years or older is projected to more than double by 2060 – accounting for about 1 in 7 people, almost all of whom will have primary health care coverage through Medicare. As such, Medicare should focus on developing new measures that assess how clinicians and health systems understand and respect patient preferences for EOL care. Some patients want to spend time with family and friends, while others place a higher priority on pain control, even if it means they may be less aware of their surroundings in their final days. Some people might give priority to receiving potentially curative treatments and life-saving interventions, while for others, the most important thing may be ensuring that they can spend their last days at home. Regardless of what a seriously ill person wants, Medicare needs new tools to assess whether these preferences are being met. <https://goo.gl/ffZ25b>

Under new legislation, advanced practice nurses signing Physicians Orders for Scope of Treatment (POST) forms

WEST VIRGINIA | *The Charleston Gazette-Mail* – 28 November 2016 – A law that allows highly trained nurses in West Virginia to treat patients and prescribe limited amounts of some drugs without supervision from physicians is having an effect in at least one area – end-of-life care (EOLC). Since June, when West Virginia House Bill 4334 went into effect, advanced practice registered nurses (APRN) have been able to ... sign Physicians Orders for Scope of Treatment (POST) documents of their patients. The forms are medical orders outlining what seriously ill patients want from EOLC. In the first three months the law has been in effect, APRNs submitted 14% of the POST forms sent to the West Virginia e-Directive Registry... In Oregon, where nurse practitioners have had the authority to sign

the forms for 15 years, a six-year study¹ ... concluded that about 11% of the POST forms submitted between 2010 and 2015 were completed by an APRN. <https://goo.gl/Vu4hkL>

Specialist Publications

'A dyadic perspective on engagement in advance care planning' (p.10), in *Journal of the American Geriatrics Society*.

'Social work involvement in advance care planning: Findings from a large survey of social workers in hospice and palliative care settings' (p.10), in *Journal of Palliative Medicine*.

1. 'The role of Advanced Practice Registered Nurses in the completion of Physician Orders for Life-Sustaining Treatment,' *Journal of Palliative Medicine*, 21 October 2016. <https://goo.gl/nH6CLI>

Cont.

Related

- CALIFORNIA | *California Healthline* – 1 December 2016 – ‘**California tests electronic database for end-of-life wishes.**’ Prompted by a state law that took effect this year, a coalition of emergency and social service providers is working to create an electronic registry for POLST forms so they will be available to first responders and medical providers when they are needed. The group is starting with a three-year pilot project in San Diego and Contra Costa counties that could serve as a model for a single, state-wide registry. Paper-based POLST forms are used across the nation, but electronic registries exist only in a few states, including Oregon, New York and West Virginia. <https://goo.gl/G4zJvE>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- IOWA | *The Des Moines Register* – 25 November 2016 – ‘**Suicide with a helping hand worries Iowans on both sides of ‘right to die.’**” The *Register* this year launched a review of national data on assisted suicide in other states, prompted by renewed political debate over efforts to make Iowa the seventh state to allow doctor-assisted suicide for terminally ill patients. But records on hundreds of deaths in the six states that allow physician-assisted suicide are non-existent or incomplete. That makes it impossible to decipher whether applicable state law was followed or if vulnerable patients suffered unintended consequences, the *Register* found. <https://goo.gl/mJ5Ljv>

International

End-of-life care in India

Palliative care providers’ lack of formal training, a painful realisation

INDIA | *The New Indian Express* (Kerala) – 29 November 2016 – Despite the fact it is mandatory for palliative care (PC) providers to have passed [the] Auxiliary Nursing & Midwife Course, besides three-month training in PC, it has emerged that nearly 1.25 lakh [i.e., 125,000] patients in the state [of Kerala], who need care to alleviate their physical agony, are being tended to by unqualified persons. Against this backdrop, the state’s Primary Level Palliative Care Programme raises questions since the community level service is mostly delivered by untrained hands. More shockingly, they carry out specialised care treatment and invasive proce-

dures without the supervision of a doctor or registered nurse. <https://goo.gl/Q1pZbS>

Specialist Publications

‘**Effective end-of-life care planning in Scotland: Culture and law**’ (p.10), in *Journal of Medical Law & Ethics*.

‘**The status of a public health approach to palliative care at New Zealand hospices**’ (p.12), in *Progress in Palliative Care*.

Spain’s low palliative care ranking in European Union due to lack of speciality

SPAIN | Agencia Efe (Madrid) – 28 November 2016 – The lack of recognition of palliative care (PC) as a medical speciality explains in part why Spain has fallen during the last decade in its ranking in Europe, according to Dr. Carlos Centeno, a member of the European Association of Palliative Care (EAPC) and a co-author of the EAPC’s 2013 ‘Atlas on Palliative Care in Europe.’^{1,2} The atlas analyzes data from the 53 member countries of the European Union. This is the second edition of this report – the first was in 2007 – which makes it possible to compare the evolution of PC in Europe. <https://goo.gl/cQRpD3>

1. Full edition: <https://goo.gl/XEltbc>

2. Cartographic edition: <https://goo.gl/w1XjCZ>

Cont.

N.B. This English summary of the Agencia Efe report paraphrases the original Spanish language version, which can be downloaded at: <https://goo.gl/BMF90D> *BRA*

Noted in Media Watch 13 June 2016, #466 (p.11):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 June 2016 – ‘**Ranking of palliative care development in the countries of the European Union.**’ The U.K. achieved the highest level of development (86% of the maximum possible score), followed by Belgium and The Netherlands (81%), and Sweden (80%). In the domain resources, Luxembourg, the U.K. and Belgium were leading. The top countries in vitality were Germany and the U.K. In comparison to 2007, The Netherlands, Malta and Portugal showed the biggest improvements, whereas the positions of Spain, France and Greece deteriorated. <http://goo.gl/B3G4Ya>

Specialist Publications

A broader understanding of moral distress

AMERICAN JOURNAL OF BIOETHICS, 2016;16(12). On the traditional view, moral distress arises only in cases where an individual believes she knows the morally right thing to do but fails to perform that action due to various constraints. They authors seek to motivate a broader understanding of moral distress. They begin by presenting six types of distress that fall outside the bounds of the traditional definition and explaining why they should be recognized as forms of moral distress. The authors then propose and defend a new and more expansive definition of moral distress and examine how it can enable the development of a taxonomy of moral distress. <https://goo.gl/hRhJ16>

N.B. This issue of the *American Journal of Bioethics* includes several articles on moral distress. Contents page: <https://goo.gl/MolRph>

“They shouldn’t be coming to the ED, should they?”

A descriptive service evaluation of why patients with palliative care needs present to the emergency department

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 30 November 2016 – Patients with palliative care (PC) needs frequently attend the emergency department (ED). There is no international agreement on which patients are best cared for in the ED, compared to the primary care setting or direct admission to the hospital. Findings [of this single centre study] challenge the misconception that patients known to a PC team should be cared for outside the ED. The importance and necessity of the ED for patients in their last years of life has been highlighted, specifically in terms of managing acute, unpredictable crises. Future service provision should not be based solely on a patient’s presenting complaint. Further qualitative research exploring patient perspective is required in order to explore the decision-making process that leads patients with PC needs to the ED. <https://goo.gl/qQL7qS>

Noted in Media Watch 2 May 2016, #460 (p.7):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 April 2016 – ‘**Effectiveness of emergency department based palliative care for adults with advanced disease: A systematic review.**’ Emergency departments (EDs) are seeing more patients with palliative care (PC) needs, but evidence on best practice is scarce. There is yet no evidence ED-based PC affects patient outcomes except for indication from one study of no association with 90-day hospital readmission, but a possible reduction in length of stay if PC is introduced early at ED rather than after hospital admission. <http://goo.gl/J18JG6>

N.B. Additional articles on end-of-life care in the emergency department are noted in Media Watch 18 April 2016, #458 (p.10).

Doctors' attitudes regarding not for resuscitation orders

AUSTRALIAN HEALTH REVIEW | Online – 25 November 2016 – There are complex barriers to the writing and implementation of not for resuscitation (NFR) orders, including doctors' knowledge around the need for consent when cardiopulmonary resuscitation is likely to be futile or excessively burdensome. Doctors (i.e., study participants) also believed that NFR orders result in changes to goals-of-care, suggesting a confounding of NFR orders with palliative care. Furthermore, doctors are willing to write NFR orders where there is clear medical indication and the patient is imminently dying, but are otherwise reliant on patients and family to initiate discussion. Hospitalised elderly patients, in the absence of an NFR order, are known to have poor survival and outcomes following resuscitation. Further, Australian data on the prevalence of NFR forms show that only a minority of older in-patients have a written NFR order in their history. In Australian hospitals, NFR orders are completed by doctors. <https://goo.gl/mRTqZ9>

Learning to care: Medical students reported value and evaluation of palliative care teaching involving meeting patients and reflective writing

BMC MEDICAL EDUCATION | Online – 25 November 2016 – The palliative care (PC) teaching at the University of Cambridge School of Clinical Medicine is multi-faceted and involves students writing reflective essays after individually meeting patients approaching the end of life during their final year general practice and hospital medicine placements. This paper draws on two studies examining this teaching element to analyse what the students found valuable about it and to comment on the practice of meeting patients and subsequent reflective writing. Overall, students reported that these components of the PC teaching are valuable. Four main themes were identified as aspects that students valued: 1) Dedicated time with patients; 2) Learning about wider elements of treatment and holistic care; 3) Practicing communication skills; and, 4) Learning about themselves through reflective writing. Some students expressed a dislike for having to formally write a reflective essay. <https://goo.gl/s9GDHB>

Challenges to access and provision of palliative care for people who are homeless: A systematic review of qualitative research

BMC PALLIATIVE CARE | Online – 3 December 2016 – Thirteen articles, reporting nine studies were identified. The challenges to access and provision to palliative care (PC) were drawn from the data covering three broad areas: “the chaotic lifestyles sometimes associated with being homeless,” “the delivery of PC within a hostel for homeless people,” and provision within “mainstream health care systems.” Obstacles were related to homeless persons competing day-to-day priorities, their experience of stigma in mainstream settings, the high burden on hostel staff in supporting residents at the end of life and inflexibility in mainstream health care systems. Suggestions for improving access to PC include building trust between homeless persons and health professionals, increasing collaboration between and flexibility within services, and providing more training and support for all professionals. <https://goo.gl/b1Vm8i>

Noted in Media Watch 8 August 2016, #474 (p.12):

- *SOCIAL WORK & SOCIETY*, 2016;14(1). ‘**Serious illness and end-of-life care in the homeless: Examining a service system and a call for action for social work.**’ In attempting to support the dignity and worth of the patients, social workers should advocate for better discharge practices, and should gain more direct familiarity with the needs of serious and chronically ill homeless individuals. <http://goo.gl/UiG8EB>

N.B. Additional articles on end-of-life care for the homeless are noted in Media Watch 14 March 2016, #453 (pp.14-15).

End-of-life care in Scotland

Does place of death vary by deprivation for patients known to specialist palliative care services?

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 1 December 2016 – Referral to, and usage of, specialist palliative care (SPC) services are not equitable and social deprivation may be a contributory factor in this. Deprivation may also affect the place of death of patients with cancer. No study, however, has investigated whether inequalities persist following referral to SPC services. Place of death and postcode were obtained for 485 consecutive patients known to SPC services within National Health Service Lothian who died in 2014-2015. From this information, deprivation quintile (DQ) was derived using the Scottish Index of Multiple Deprivation (SIMD) database and place of death compared between DQs and analysed statistically. Findings suggests even after referral to SPC services variation in place of death by deprivation persists. Greater deprivation is associated with increased likelihood of dying in hospital and decreased likelihood of dying in a hospice: no difference was noted for home deaths. <https://goo.gl/VXLHKT>

Noted in Media Watch 24 June 2013, #311 (p.5):

- NATIONAL COUNCIL FOR PALLIATIVE CARE | Online – 20 June 2013 – '**Deprivation and end of life care.**' New analysis from the Office for National Statistics from the National Bereavement Survey 2011 (VOICES) has been published which shows an apparent link between deprivation and the quality of end-of-life care (EOLC) received.¹ Significantly more bereaved respondents of patients living in the least deprived areas rated the standard of overall EOLC as excellent (44%) compared with respondents of patients living in the most deprived areas (39%). <https://goo.gl/9SZZSS>

1. *National Bereavement Survey (VOICES) by Area Deprivation, 2011*, Office for National Statistics, June 2013. <https://goo.gl/zqJgZn>

Palliative care interventions in advanced dementia

COCHRANE DATABASE OF SYSTEMATIC REVIEWS | Online – 2 December 2016 – The authors found only two suitable studies (189 people) ... [and identified] ... six studies that were underway, the results of which were not yet published. One study found having a small team of doctors and nurses trained in palliative care (PC) made little difference to how people with advanced dementia were treated while in hospital. But, having this special team meant that more people had a PC plan when they were discharged from hospital. The other study measured if giving written information to relatives explaining the different methods that can be used to feed people with advanced dementia helped either the relatives or the person; this study found that giving relatives this information made it a little easier for relatives to make decisions about what methods would be used to feed the person with dementia. The two PC methods in these studies were very different. The authors cannot be certain about how accurate either of these results reported here are, partly because only a small number of people took part in the studies. So from this, it is hard to be sure whether PC makes a difference to people with advanced dementia. <https://goo.gl/Q2gBnb>

Noted in Media Watch, 1 August 2016, #473 (p.11):

- *DEMENTIA* | Online – 26 July 2016 – '**The extended palliative phase of dementia: An integrative literature review.**' There was no consistent definition of advanced dementia. The extended palliative phase was generally synonymous with end-of-life care. A lack of understanding of palliative care among frontline practitioners was related to a dearth of educational opportunities in advanced dementia care. <http://goo.gl/ujukhx>

N.B. Additional articles on end-of-life care for people living with dementia noted in Media Watch 4 July 2016, #469 (pp.15-16).



Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

Interventions for promoting participation in shared decision-making for children with cancer

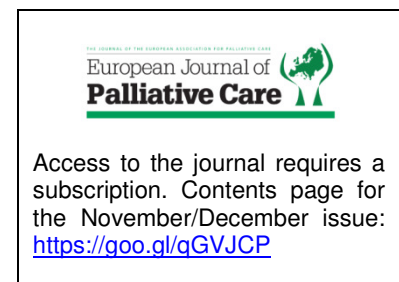
COCHRANE DATABASE OF SYSTEMATIC REVIEWS | Online – 29 November 2016 – This is an update of the Cochrane systematic review of shared decision-making (SDM) making published in 2013.¹ Children's rights to have their views heard in matters that affect their lives are now well established since the publication of the UN Convention treaty (1989). Children with cancer generally prefer to be involved in decision-making and consider it important that they have the opportunity to take part in decision-making concerning their health care, even in end-of-life decisions. There is considerable support for involving children in healthcare decision-making at a level commensurate with their experience, age and abilities. Thus, healthcare professionals and parents need to know how they should involve children in decision-making and what interventions are most effective in promoting SDM for children with cancer. No conclusions can be made on the effects of interventions to promote SDM for children with cancer aged four to 18 years. This review highlights the dearth of high-quality quantitative research on interventions to promote participation in SDM for children with cancer. <https://goo.gl/YgAUW8>

1. 'Interventions for promoting participation in shared decision-making for children with cancer,' *Cochrane Database of Systematic Reviews*, 6 June 2013. <https://goo.gl/Ruq2eh>

N.B. Additional articles on the "child's voice" in end-of-life care are noted in Media Watch 26 September 2016, #481 (p.3, p.7).

Paediatric palliative nursing: The tension between closeness and professional distance

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(6):278-280. Nurses who gain enough experience to understand their own vulnerabilities and resources, and who address the tension between them from a professional perspective, can increase the range of their abilities and set clear boundaries between themselves and the child. Inexperienced nurses may find it difficult to maintain a professional relationship and draw boundaries. It is essential for nurses to be able to acknowledge and communicate the end-of-life scenario. Relationships with dying children and their families are a key factor in nursing quality. Nurses need a way to express their emotional distress and thus overcome their potential isolation; they can do this by recounting their traumatic experiences to others, which reassures them that the child is not forgotten.



Does current U.K. research address priorities in palliative and end-of-life care?



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(6):290-293. Published in 2015, the Palliative and end-of-life care (EOLC) Priority Setting Partnership (PeolcPSP) report is being used to guide palliative and EOLC research funding. The authors have reviewed an open database of 2014 U.K. health research grant data to identify if and how current research is addressing the 83 PeolcPSP questions. The aims of this project include helping researchers avoid duplication by highlighting current research and fostering collaboration by showing who is already active in addressing specific questions. This project highlights that research spending in palliative and EOLC remains low, with pockets of good news. It also highlights the need for more research proposals and testing interventions to tackle the problems encountered in palliative and EOLC. The number one PeolcPSP priority – how to provide palliative care out of hours – is one of the questions most in need of further research investment. Of the 83 questions, 19 are not addressed by any directly related research funding active in 2014.

Cont.

Noted in Media Watch 11 May 2015, #409 (p.8):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(3):114-117. **'Identifying palliative and end-of-life care research priorities: A U.K. approach to consult end users.'** Launched in 2013 the Palliative & End-of-Life Care Priority Setting Partnership (PeolcPSP) has enabled end users of research – patients, carers and clinicians – to identify their priorities in order to inform future end-of-life care research.

N.B. Additional articles on research priorities in the context of end-of-life care are noted in Media Watch 31 October 2016, #485 (p.5).

Mindfulness meditation and pain management in palliative care



EUROPEAN JOURNAL OF PALLIATIVE CARE, 2016;23(6):294-297. Pain is one of the main symptoms reported in palliative care (PC) and has a huge impact on quality of life. Mindfulness meditation (MM) is receiving increased interest, along with other non-pharmacological interventions, for its potential to control pain and maximise patient functionality in PC. Research shows MM is able to affect pain perception by modifying the activation of specific brain areas. However, more studies in palliative settings are needed. MM can restore a sense of control “over pain and circumstances,” which is often lost in PC patients.

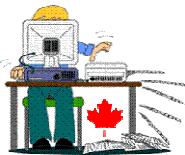
The challenges of implementing a multi-centre audit of end-of-life care in care homes

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING | Online – 25 November 2016 – The audit was a retrospective multi-centre survey of bereaved relatives/next-of-kin of residents who died in the care home, using an anonymous, validated questionnaire: the Family Perception of Care Scale. Questionnaires were sent 3-months after bereavement. The care homes were in areas encompassing outer and inner city populations. The team identified eight challenges to the audit process, in particular, embedding procedures within the care homes, non-responses and developing action plans for improvement. Overall, the audit provided an indication of where improvements could be made and where care was already excellent, built confidence and increased expertise in the care home staff. <https://goo.gl/3a3yb3>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 November 2016 – **'Goals of care or goals of trust? How family members perceive goals for dying nursing home residents.'** [In this study] family members' experience of decision making and death differed based on the presence or absence of trusting relationships with nursing home staff. Family members who reported trust described a positive end-of-life experience and less need for prescribed goals of care discussions. In the absence of trust, family members reported that goals of care discussions were ignored by staff or created confusion. <https://goo.gl/irlZNq>

N.B. Additional articles on end-of-life care in care/nursing homes are noted in Media Watch 7 November 2016, #486 (p.9).



[Barry R. Ashpole](#)

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://goo.gl/5CHoAG>

A dyadic perspective on engagement in advance care planning

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 2 December 2016 – In interviews conducted with both the veteran and surrogate, they were asked to discuss their participation in four advance care planning (ACP) activities: 1) Communication about life-sustaining treatment; 2) Communication about views on quality of life; 3) Completion of a living will; and, 4) Appointment of a healthcare proxy. They were asked about barriers to and facilitators of ACP engagement. When they did not agree about engagement, they each provided their perspective on what they believed had or had not occurred. Many of the same barriers to and facilitators of engagement were discussed by both patients and surrogates. These included difficulty thinking about dying, differences in values, and experiences with others that demonstrated the ability of ACP to decrease burden or avoid conflict. Reasons for disagreements in perceptions about whether communication had occurred included surrogates' need for more detailed information, surrogates' lack of readiness to hear what the patient was saying, and surrogates' reliance on what they know about the patient. For some dyads, participation in the study prompted additional communication, resulting in a better shared understanding of ACP engagement. <https://goo.gl/NnwpMQ>

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 December 2016 – '**Social work involvement in advance care planning: Findings from a large survey of social workers in hospice and palliative care settings.**' Most respondents report that social workers are responsible for educating patients/families about ACP options (80%) and are the team members responsible for documenting ACP (68%). Compared with other settings, oncology and inpatient palliative care social workers were less likely to be responsible for ensuring that patients/families are informed of ACP options and documenting ACP preferences. <https://goo.gl/JZ7wPH>

Effective end-of-life care planning in Scotland: Culture and law

JOURNAL OF MEDICAL LAW & ETHICS | Inprint – Accessed 29 November 2016 – In the context of an ageing population, end-of-life care planning is increasingly important. The law in Scotland does not, as yet, take the active and specific steps to help address this evident in other jurisdictions. The author contends there are two particular issues which need to be addressed: 1) Normalising the idea of a discussion about dying, such that individuals feel entitled to discuss and plan for it by way of an advance directive (AD), feel it is a valuable exercise, and feel reassured their plans will not falter if they lose capacity; and, 2) Formulating an approach which prompts and encourages that discussion, but also promotes autonomous decision-making. She asserts the law can, and should help with this by providing a legislative basis for AD in order to set out the requirements for formal validity, and by making provision for an allied, non-mandatory pro-forma to guide and assist those who wish to use it. <https://goo.gl/xZRzUe>

Noted in Media Watch 26 September 2016, #481 (p.4):

- U.K. (Scotland) | *Holyrood* (Edinburgh) – 20 September 2016 – '**Person-centred care in Scotland: Palliative care.**' The Chief Medical Officer ... thinks palliative discussions can reveal the "disconnect" between what a person wants towards the end of their life and what a clinician sometimes assumes the person wants. The changes to the national policy on do not attempt cardiopulmonary resuscitation followed reviews by doctors and nursing unions as well as guidance from the General Medical Council.¹ A report for the Scottish Parliament's Health & Sport Committee revealed in many cases, palliative conversations were not taking place until it was too late.² <https://goo.gl/WvWmWb>

1. 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR),' Government of Scotland, August 2016. [Noted in Media Watch 5 September 2016, #478 (p.15)] <http://goo.gl/DO1q0m>

2. 'International comparisons in palliative care provision: What can the indicators tell us?' Health & Sport Committee, Health & Sport Committee, Scottish Parliament, September 2015. [Noted in Media Watch 21 September 2015, #428 (p.6)] <http://goo.gl/KhqqtqU>

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

Events leading to hospital-related disenrollment of home hospice patients: A study of primary caregivers' perspectives

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 November 2016 – Approximately 25% of hospice disenrollments in the U.S. occur as the result of hospitalization, which can lead to burdensome transitions and undesired care. Research examining hospital-related disenrollment among these patients is limited. Thirty-eight semi-structured phone interviews with caregivers were conducted and data regarding the events leading to hospitalization and hospice disenrollment were collected. Content analysis revealed four major themes contributing to hospitalization: 1) Distressing/difficult-to-witness signs and symptoms; 2) Needing palliative interventions not deliverable in the home setting; 3) Preference to be cared for by non-hospice physicians or at a local hospital; and, 4) Caregivers not comfortable with the death of their care recipient at home. <https://goo.gl/4qWXhA>

Palliative care needs of young adults with life-limiting conditions

MEDSCAPE | Online – 1 December 2016 – Young adults may represent a small segment of the population requiring palliative care (PC), yet those with serious, life-limiting conditions have significant needs for this care. Cook and colleagues report their findings from a study exploring the needs of 10 young adults (age range, 19-29 years) who had limited expectations of surviving past age 30.¹ The data were derived from an online focus group that captured some insightful themes about the unique needs of this population of young adults. These themes, which explored the many physical and psychosocial needs of this group, included “investing in uncertainty” and “if we focus on what we can't do, we'll never get anywhere.” Participants described the many obstacles to achieving educational goals or gaining employment while being aware of the reality that their remaining years were limited. They shared thoughts about volunteering or seeking other ways to contribute or find meaning in their lives. They also shared their feelings about socializing and intimacy, important experiences for young adults that are often thwarted by serious illness. Another key theme was living with uncertainty, a concept frequently discussed in PC, yet one with special significance to this population. <https://goo.gl/kNM46j>

1. 'Investing in uncertainty: Young adults with life-limiting conditions achieving their developmental goals,' *Journal of Palliative Medicine*, 2016;19(8): 830-835. <https://goo.gl/f7pWEx>

Palliative care: Lemonade from lemons – exploring the results of the VOICE study

NATURE REVIEWS CLINICAL ONCOLOGY | Online – 29 November 2016 – The VOICE (Values & Options in Cancer Care) study addresses the oncologist-patient dyad by adding a two-sided intervention. Results of this ... study are, at best, limited and, at worst, cosmetic because clinically relevant long-term outcomes were unaffected. VOICE is the first attempt at addressing complexity in this genre of studies and, even with its shortcomings, teaches us some important lessons. <https://goo.gl/HQpHVv>

N.B. The VOICE study, an initiative of the U.S. National Cancer Institute, is intended to improve communication and self-awareness by coaching patients with advanced cancer, family caregivers and physicians to communicate more effectively.



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.
<http://goo.gl/OTpc8l>

Health care professionals' understandings of cross-cultural interaction in end-of-life care: A focus group study

PLOS ONE | Online – 23 November 2016 – The health care professionals interviewed talked about cross-cultural interaction in end-of-life care (EOLC) as interaction that brings about uncertainty, stress and frustration even though they had limited experience of this type of interaction. The focus group discussions brought attention to four specific challenges that they expected to meet when they care for patients with migrant backgrounds since they took for granted that they would have an ethno-cultural background that is different to their own. These challenges had to do with communication barriers, “unusual” emotional and pain expressions, the expectation that these patients’ families would be “different,” and the anticipation that these patients and their families lack knowledge. At the core of the challenges in question is the idea that cross-cultural interaction means meeting “the unknown.” In addition, the EOLC professionals interviewed talked about patients whose backgrounds they did not share in homogenizing terms. It is against this backdrop that they worried about their ability to provide EOLC that is individualized enough to meet the needs of these patients. <https://goo.gl/wKc1v8>

Related

- *DIVERSITY & EQUALITY IN HEALTH AND CARE* | Online – Accessed 3 December 2016 – ‘**Cultural competency: Best Intentions are not good enough.**’ Racism is a health care issue, a disease of the mind and soul, and should be treated as such. Cultural competency improvement initiatives should not only address the symptoms (what most training does now), but also address causes. A broader more inclusive perspective is required to clarify foundational issues, expand understanding and intrinsically incentivize attitude and behavior change. While there are multitudes of noble efforts underway to address inequities in healthcare (in policy, resource allocation, and provider, training to name a few) some of this work misses the mark. The primary reason, “No problem can be solved from the same level of consciousness that created it,” as Albert Einstein so adeptly warns. <https://goo.gl/4FVtBK>

The status of a public health approach to palliative care at New Zealand hospices

PROGRESS IN PALLIATIVE CARE | Online – 1 December 2016 – There is growing international support for a public health approach to palliative care (PC); however, the status of the movement in the New Zealand context is unknown. Analysis of the quantitative results [of this mixed method study] confirmed that a public health approach to PC was a current priority at 60% of New Zealand hospices. However, both phases of the study demonstrated that community engagement, one of the chief out-workings of a public health approach to PC, was incompletely understood and practised. Furthermore, the qualitative results showed that, while this approach is supported, there are significant barriers to implementation, including paternalism, resource constraints, adequate evaluation, and incomplete understanding of key concepts, such as social networking and community engagement. This study is the first to explore the extent to which a public health approach to PC is supported by hospices in New Zealand. The unique new findings show that there is need for the model to be recognized in policy. Related to practice, if the model is to be implemented to maximum benefit, further conceptual clarity of the key tenets is needed. In addition, addressing the barriers to implementation identified by this study will need to be prioritized by hospice leadership. <https://goo.gl/DCcXTI>

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.**’ The search identified 18 studies. A thematic synthesis of these identified three different paradigms of a public health approach to palliative care (PC) within the current empirical research. These were defined as a health-promotion approach focused on empowerment at community level, a World Health Organisation approach which focused on systems at country level, and a population-based approach which typically viewed PC issues from an epidemiological perspective. <http://goo.gl/4EGYB0>

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

The dying role: Its relevance to improved patient care

PSYCHIATRY, 2016;79(3):199-205. Society is failing to meet the obligation it has to its dying members. Persons with terminal illness suffer isolation and neglect in hospitals, receive overzealous treatment by physicians, and are kept in ignorance of their situation by families and medical personal. Evidence for these statements has come from observers of the medical care system and from dying patients themselves... In the nineteenth century it was common for persons to die in the familiar environs of their homes, surrounded by grieving families from whom they parted in a meaningful manner... Dying persons today no longer fill a well-defined social role. Instead, the distinction between the roles of sick and dying persons has been lost and, in the resulting confusion, the care of dying people has suffered. The purpose of this article is to clarify

the distinction between the dying and sick roles, identify the signs of existing role confusion, suggest ways in which this confusion may be corrected, and show how re-establishment of the dying role can result in improved care for dying people. The important part physicians play in defining sick and dying roles is emphasized. <https://goo.gl/tlhBY>



PSYCHIATRY
INTERPERSONAL AND
BIOLOGICAL PROCESSES
A Journal of the Washington School of Psychiatry

Several articles in the latest issue focus on "the dying role." Journal contents page: <https://goo.gl/fqV0sl>

Related

- *BUNDESGESUNDHEITSBLATT – GESUNDHEITSFORSCHUNG – GESUNDHEITSSCHUTZ (Federal Health Gazette – Health Research – Health Protection)* | Online – 28 November 2016 – ‘**Dying and death in societal transformation.**’ In late modern societies there are many different views of what “successful” or “good” dying means. This change is described by the following seven theses: 1) We live longer and we die longer; 2) We no longer die suddenly and unexpectedly, but slowly and foreseeably; 3) Even though our biological life on earth has become longer, our life has been shortened by the loss of eternity; 4) We no longer die on the stage of ritualized relationships with our family and neighbours, but behind the curtains of organizations; 5) We live and die in a society of organizations and have to get organized for the final phase of our life; 6) Living and dying are no large, state-owned enterprises, but small, private enterprises; 7) The hospice movement as well as palliative medicine have created public awareness, made dying a matter of discussion, and offered a new set of options. <https://goo.gl/C5AuNF>

N.B. German language article.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BUNDESGESUNDHEITSBLATT – GESUNDHEITSFORSCHUNG – GESUNDHEITSSCHUTZ (Federal Health Gazette – Health Research – Health Protection)* | Online – 28 November 2016 – ‘**Assisted suicide in the movies – what is (not) shown?**’ Since the mid-1980s, the theme of assisted suicide has repeatedly been taken up by cinema, predominantly as central to a relationship drama. A sick person asks somebody close to them for help. Often this somebody is a physician or a nurse, ultimately an obvious way of solving the practical problem of how the assistant is to gain access to a lethal substance. At the same time, this constellation enables a physician or nurse to be forced into a dramatic conflict between professional ethics and a personal obligation towards a loved one. Alongside more classic clinical pictures such as terminal cancer, recent films about assisted suicide have featured neurodegenerative diseases and physical disabilities. Another new development is that elderly patients are no longer alone in requesting assistance; films also and increasingly portray young adults. Besides a fear of unbearable pain, more recent films have also increasingly addressed the worry that permanent nursing might be required, as well as the subjectively experienced loss of dignity. The possibilities offered by palliative care hardly play a role in feature films. <https://goo.gl/yx5Oly>

N.B. German language article.

Cont.

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 29 November 2016 – ‘**International Association for Hospice & Palliative Care Position Statement: Euthanasia and Physician-Assisted Suicide.**’ Reports about regulations and laws on euthanasia and physician assisted suicide (PAS) are becoming increasingly common in the media. Many groups have expressed opposition to euthanasia and PAS while those in favor argue that severely chronically ill and debilitated patients have a right to control the timing and manner of their death. Others argue that both PAS and euthanasia are ethically legitimate in rare and exceptional cases. Given that these discussions as well as the new and proposed laws and regulations may have a powerful impact on patients, caregivers, and health care providers, the International Association for Hospice & Palliative Care (IAHPC) has prepared this statement. IAHPC believes that no country or state should consider the legalization of euthanasia or PAS until it ensures universal access to palliative care services and to appropriate medications, including opioids for pain and dyspnea. <https://goo.gl/xVBszw>
- *MCGILL JOURNAL OF LAW & HEALTH*, 2017;10(1):S1-S33. ‘**Carter, medical aid in dying, and mature minors.**’ This article surveys jurisdictions where minors are included in physician-assisted dying regimes and identifies what little empirical evidence exists regarding requests from minors. The heart of the article considers the jurisprudence on mature minors and when they are deemed to have the right to require the withdrawal of, or refuse to receive, life-sustaining treatment, and compares the reasoning in these cases with that in *Carter v Canada (AG)*. A particular focus is on how the jurisprudence approaches decisional capacity when the individual in question may be particularly vulnerable. It finds that a blanket exclusion of mature minors from a physician-assisted dying regime likely violates the Canadian Charter of Rights & Freedoms, and calls out for considered debate on these issues instead of forcing a minor and their family to bring the issues forward through litigation. <https://goo.gl/w5dHyU>

N.B. Click on the title of the article under ‘Announcements’ to access full text.

[Media Watch: Editorial Practice](#)

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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.

Worth Repeating

Difficult and uncomfortable conversations

Demand of words

JAMA INTERNAL MEDICINE | Online – 1 April 2013 – In medicine, there is a brittle demand of words – once spoken, they cannot be called back, for their footprint is forever – particularly at the end of life. They embed themselves in the hearts of patients and families and hold dominion over understanding or uncertainty, acceptance or denial. They can also hurt or heal, or harm or help, and bear witness to the suffering of disease – and the manner of the physician. Patients and families are often distressed, in shock, and grieving, and frequently waiting to hear the words they don't want to hear. And physicians don't want to say the words – it's disheartening and stressful. Moreover, the emotional content of words and the asymmetrical and often times paternalistic relationship between physician and patient can become overwhelming and unbearable, exaggerating vulnerability and fear, and further contributing to difficult and uncomfortable conversations. Unfortunately, many physicians have a “dis-ease” caring for certain ailments and may be adversely affected by a clinical impotence to cure a life-threatening illness. This clinical impotence can bring about an unintentional detached remoteness, and far-too-often, time away from the bedside. [Noted in Media Watch 15 April 2013, #301 (p.12)] <https://goo.gl/hwDFsr>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/WAbX4S>

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

PALLIATIVE CARE NETWORK COMMUNITY: <http://goo.gl/8JyLmE>

PALLIMED: <http://goo.gl/7mrgMQ> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <https://goo.gl/JL3j3C>

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNC7>

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://goo.gl/o7kN3W> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1I9K>

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

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