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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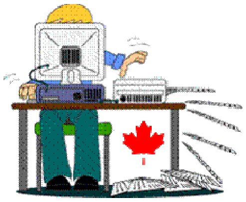

Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to Specialist Publications and 'Striving for a balance between leading and following the patient and family: Nurses' strategies to facilitate the transition from life-prolonging care to palliative care...' (p.6), in *BMC Palliative Care*.

Canada

Stressed and exhausted caregivers need better support

THE CONVERSATION | Online – 5 April 2018 – Brenda is one of 8.1 million Canadians who have taken on challenging unpaid roles – as informal caregivers for people living with physical or cognitive conditions or chronic life-limiting illnesses.[1] Her stress increased as her parents started to deteriorate physically and mentally. She tried to stay ahead of the ever-changing situation, but became exhausted after her dad started waking in the middle of the night and getting dressed to go out. She looked on the internet for support in her care-giving role. Research shows that current health and social services do not address the complex needs of older adults or their family caregivers.[2] It also suggests that web-based interventions may help reduce depressive symptoms, anxiety and stress or distress for these caregivers.[3] Older adults with chronic conditions rely heavily on their family caregivers to coordinate their care, monitor medication and accompany them to appointments. In fact, 70-80% of community care for older adults is provided by informal caregivers as opposed to formal care providers. Increasingly, these older adults have multiple chronic conditions, such as dementia and stroke, not just one. And as this prevalence of multiple conditions increases worldwide, it's associated with poor health and higher health-care use and costs. Women represent a slight majority of Canadian caregivers at 54% and spend more time per week on caregiving than males.[4] Caregivers report that they do not receive adequate home care or respite services to support them in their roles. https://goo.gl/dVhCUN

Specialist Publications

'Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents' (p.7), in *BMJ Open.*

'Later-life homelessness as disenfranchised grief' (p.7), in *Canadian Journal on Aging.*

'Adolescent decision-making in Canadian medical contexts: Integrating neuroscience and consent frameworks' (p.10), in *Paediatrics & Child Health.*

'Exploring attitudes toward physician-assisted death in patients with life-limiting illnesses with varying experiences of palliative care: A pilot study' (p.11), in *BMC Palliative Care.*

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[1] 'Carers contribute $25 billion in unpaid labour to our health system,' Carers Canada (Canadian Home Care Association), 2009. https://goo.gl/ctfRPx

Cont.

2. 'Managing multiple chronic conditions in the community: A Canadian qualitative study of the experiences of older adults, family caregivers and healthcare providers,' *BMC Geriatrics*, published online 31 January 2018. **Full text:** https://goo.gl/ASe2fh

3. 'Web-based interventions to improve mental health, general caregiving outcomes, and general health for informal caregivers of adults with chronic conditions living in the community: Rapid evidence review,' *Journal of Medical Internet Research*, 2017;19(7):e263. **Full text:** https://goo.gl/C5cF6R

4. 'Portrait of caregivers 2012,' Statistics Canada, 2013. [Noted in the 8 April 2013 issue of Media Watch (#300, p.2)] https://goo.gl/nc2Cpt

U.S.A.

A harder death for people with intellectual disabilities

THE NEW YORK TIMES | Online – 5 April 2018 – In New Hampshire ... and in many other states, legal guardians of people with intellectual disabilities can make most medical decisions but, by law, they cannot decline life-sustaining therapies like mechanical ventilation. These laws are meant to protect patients with disabilities from premature discontinuation of life-saving care. Yet, my patient was experiencing the unintended downside of these laws: the selective prolonging of unpleasant and questionably helpful end-of-life (EoL) care in people with disabilities. For my patient's guardian to discontinue unwanted life-sustaining therapies, she had to petition a probate court judge. Busy court dockets being what they are, this can take weeks. Once in court, the judge asks questions aimed at making the right legal decision. How sure is the guardian or family member of the patient's wishes? What's the doctor's best estimate at a prognosis? Often the judge will ask an ethicist like me to weigh in on whether withdrawal is an ethically permissible option. Then the judge makes a decision. This slow, impersonal, courtroom-based approach to EoL decision-making is a far cry from the prompt, patient-centered, bedside care that all of us deserve. This legalistic approach to EoL decision-making also creates unreasonable expectations of legal guardians. https://goo.gl/W5e7Qc

Noted in Media Watch 1 August 2016 (#473, p.14):

- *JOURNAL OF APPLIED RESEARCH IN INTELLECTUAL DISABILITIES* | Online – 25 July 2016 – **'Intellectual disabilities and decision making at end of life: A literature review.'** Individuals with an intellectual disability are vulnerable to having end-of-life (EoL) decisions made for them merely due to the presence of a disability. As a result, decisions made by others may not reflect the exact wishes of the individual. The findings from this review provide a foundation for a decision tree in EoL decision making for individuals with an intellectual disability. **Abstract:** http://goo.gl/sCALxr

N.B. Articles on end-of-life care for people living with intellectual disabilities noted in the 26 March 2018 issue of Media Watch (#556, p.14).

Buyers snatch up unprofitable hospices…

HOME HEALTH CARE NEWS | Online – 4 April 2018 – When it comes to mergers and acquisitions, hospice is hot – really hot. In fact, some new buyers entering the market are coming into the space purely because of the tailwinds and strong demographics, even if the operations they purchase aren't profitable. The hospice sector has seen gradual Medicare reimbursement increases over the last few years, while home health care, in comparison, has seen cuts. Part of the driving interest is that the hospice market is "underserved"... Payers love hospice because it costs significantly less than most other care typically provided in the last six months of life. Patients who opt to utilize hospice can have many of the services brought to them and are less likely to wind up in the emergency room. Not all hospice acquisitions are being driven by investors looking for a return; there are also strategic acquisitions taking place, involving some of the nation's largest providers of in-home care. https://goo.gl/m6aT9W

Cont.

Related

- FACTS WEEK | Online – 5 April 2018 – **'Hospice services market to undertake strapping growth during 2017-2025.'** The factors driving the growth of the global hospice services market are expanding population pool of aged people, increasing caseload of serious life threatening diseases such as cancer, end stage renal disease, heart failure and respiratory failure, rising awareness and adoption rate of hospice services, increase in number of private, government, government aided and non-profit organisations providing hospice care services. https://goo.gl/Eux2SM

Nation's top pain doctors face scores of opioid lawsuits

YAHOO FINANCE | Online – 3 April 2018 – Four of the nation's leading pain doctors, who spearheaded a medical movement to treat chronic pain with opioid drugs, have been named as co-defendants in scores of lawsuits filed by cities and counties against opioid manufacturers. The lawsuits allege that the doctors allowed themselves to be used by manufacturers, as part of a false, industry-wide marketing campaign, thereby helping to instigate the public health crisis that has led to more than 300,000 opioid-related overdose deaths since 2000. Because they allegedly accepted tens of thousands of dollars from opioid manufacturers – for research, consulting, speeches, honoraria, and continuing medical education seminars – and led organizations that also received substantial industry funding, plaintiffs lawyers assert that their messages became tainted, and that they overstated the drugs' efficacy, and understated their risks in ways that were scientifically unsupportable. https://goo.gl/7X6REw

Related

- TEXAS | *The Tyler Morning Telegraph* – 2 April 2018 – **'Hospice and substance abuse prevention coalitions partner to safely dispose of leftover prescriptions.'** Hospice of East Texas and Next Step Community Solutions are partnering in an effort to keep unused prescriptions drugs away from people who could abuse them. The hospice serves about 2,000 patients per year in the East Texas area. Much of the coverage area overlaps with Next Step's coverage area under its substance abuse coalition program. https://goo.gl/xPBrDc

N.B. Reports on opioid shortages in U.S. hospitals and hospices noted in the 19 March 2018 issue of Media Watch (#555, p.2). Additional articles on the consequences of stricter controls on opioid use in the U.S., in the context of hospice and palliative care, noted in the 19 and 12 February 2018 issues of Media Watch (#551, p.4, and #550, p.4, respectively).

Many doctors don't pay attention to home health care plans

REUTERS | Online – 2 April 2018 – Physicians charged with approving treatment plans for skilled home health care often spend no more than a minute reviewing the plans, a study of U.S. doctors suggests.[1] Researchers surveyed 1,005 physicians who specialize in geriatrics, family or general medicine, or hospice and palliative care. Overall, 720 respondents, or 72%, said they had certified at least one plan for skilled home health care in the previous year for a patient covered by Medicare, the U.S. health program for adults 65 and older. Among the doctors who certified these plans, 47% spent less than one minute reviewing the paperwork before signing off on it... Only 21% of physicians reported spending two minutes or more. Skilled home health care services may be ordered by physicians for homebound patients who need support from nurses, physical therapists or occupational therapists to manage daily tasks and recover from injuries or illnesses. https://goo.gl/X5DeEA

1. 'Interactions between physicians and skilled home health care agencies in the certification of Medicare Beneficiaries' Plans of Care: Results of a nationally representative survey,' *Annals of Internal Medicine*, published online 3 April 2018. **Abstract:** https://goo.gl/n6nKb6

Media Watch Online: Updated 31 March 2018

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.12.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- HAWAII | Hawaii Public Radio (Honolulu) – 5 April 2018 – '**"Death with Dignity" signed into law.**' Hawaii joined seven other states to offer terminally ill adults the option of obtaining lethal doses of prescription drugs to end their lives. Before signing the measure into law, Governor David Ige said the issue has been discussed for more than 20 years, but the final bill puts the patient in charge. Patient safeguards include medical and mental health verifications, disinterested witnesses, and patient self-administration of drugs. https://goo.gl/Wai9d1

- STATE OF NEW YORK | *The Adirondack Daily Enterprise* (Saranac Lake) – 2 April 2018 – '**Medical Aid in Dying Act updated.**' This Act allows a terminally ill, mentally capable adult to request life-ending medication from a doctor that the person can take at a time of his or her choosing, or never, should suffering become unbearable, so long as he or she can self-administer it. A number of amendments [detailed in this report] have been made to the Medical Aid in Dying Act. https://goo.gl/xc1cVB

International

End-of-life care in South Korea

Thousands suspend life-sustaining treatment after well-dying law implemented

SOUTH KOREA | KBS World Radio (Seoul) – 6 April 2018 – More than three-thousand patients have forgone life-prolonging treatment since the Hospice, Palliative Care & Life-sustaining Treatment Decision-making Act, commonly known as the well-dying law, went into effect two months ago. According to the Ministry of Health & Welfare and the Korea National Institute for Bioethics Policy, a total of 3,274 terminally ill patients withheld or suspended life-sustaining treatment between 4 February, when the well-dying law took effect, and 3 April. https://goo.gl/BQdBYd

End-of-life care in England

"Terminally ill patients are dying in hostels": Hackney GP reveals health toll of housing crisis

U.K. (England) | *The Hackney Gazette* – 4 April 2018 – Dr. Claire Davies has been at the frontline of treating health problems linked with inadequate housing in the borough [of Hackney] and says people in hostels can easily end up on the edge of society. Dr. Davies highlights a study published ... last July which found terminally ill people are dying without support in hostels.[1,2] The research, carried out in [the Boroughs of] Hackney, Lambeth and Westminster, was the largest study of its kind. It showed hostel staff often end up caring for some of the sickest homeless people, despite not having palliative care (PC) training or support to do so. "People that are homeless have a much, much shorter life expectancy, so they may be dying of cancer, they may be dying of end stage liver disease due to things like alcohol misuse or liver viruses, and people are having PC in hostels," said Dr. Davies. https://goo.gl/ooV7bp

Specialist Publications

'Later-life homelessness as disenfranchised grief' (p.7), in *Canadian Journal on Aging*.

1. 'Homeless patients are dying without support,' Marie Curie Palliative Care Research Department, University College London, April 2017. https://goo.gl/jPH5bA

2. 'End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care,' *Palliative Medicine*, published online 3 July 2017. [Noted in the 10 July 2017 issue of Media Watch (#520, p.5)] **Full text:** https://goo.gl/b3eQ42

End-of-life care in England

Hospices to create unique new partnership

U.K. (England) | *The Oldham Evening Chronicle* – 4 April 2018 – Hospices across Greater Manchester (GM) are leading the way with a unique partnership to help influence the future provision of specialist palliative and end-of-life care (EoLC) for local people. The GM Hospices Initiative, the first of its kind in the U.K., sees GM's seven adult hospices ... working together to promote the inclusion, assimilation and commissioning of specialist palliative and EoLC provided in the area. https://goo.gl/77V4ig

End-of-life care in Australia

Should a doctor always disclose prognosis?

AUSTRALIA (New South Wales) | *The Guardian* (Surry Hills) – 3 April 2018 – In the 1960s, 90% of oncologists admitted they would not disclose a terminal cancer diagnosis to a patient. Twenty years later, 90% said they would. Today, in the era of patient autonomy, full disclosure is painted as a moral absolute, but my experience [as an oncologist] has shown me a more nuanced reality. In many cultures, it is a filial duty to make medical decisions on behalf of a parent. Doctors might bypass a patient and speak first to the adult children and patients willingly concede this onerous role to their children. Decisions about treatment are not solely about the individual, but also about the family unit. Doctors should not generalise based on culture, language or their own past experience. It's fine for patients to bypass the brutal details of their illness even if the evidence shows that they are not as traumatised by disclosure as we fear. We will never know what patients want if we fail to ask. We should assume nothing, but respect an individual's decision to know only so much. Navigating this fine line comprises the art of medicine. https://goo.gl/fXBHC8

Specialist Publications

'Perhaps quality of life should not be used as a trigger for discussing resuscitation and advance care plans' (p.8), in *Emergency Medicine Australasia.*

'How and when do patients request life-expectancy estimates? Evidence from hospice medical consultations and insights for practice' (p.11), in *Patient Education & Counseling.*

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The focus of the April 2018 issue of the @Carsearch newsletter is cultural diversity for end-of-life and palliative care. **Download/view at:** https://goo.gl/y7b3pw

Diabetes end-of-life care recommendations updated

DiABETES UK

U.K. (England, Scotland & Wales) | *The Diabetes Times* – 2 April 2018 – The third edition of the 'End of Life Diabetes Care: Clinical Care Recommendations' has been published to reflect latest evidence.[1] The document aims to summarise a consistent, but high-quality approach towards end-of-life (EoL) care for people with diabetes by providing a series of clinical care recommendations. Professor Alan Sinclair, one of the authors, said: "This updated guidance summarises the major clinical problems that individuals with diabetes at the EoL experience and how these are best managed. "We have provided additional information on the early identification of those entering an EoL scenario, a new section on special populations such as those who are frail or demented, or residing in a care home, additional guidance relating to those with cancer and renal failure on dialysis, and updated our guidance on advance care directives." https://goo.gl/SQRwuw

1. 'End of Life Diabetes Care: Clinical Care Recommendations, Diabetes UK, March 2018. **Download/ view at:** https://goo.gl/H8ifg7

Cont.

Noted in Media Watch 6 November 2017 (#537, p.8):

- *DIABETES RESEARCH & CLINICAL PRACTICE* | Online – 30 October 2017 – '**Palliative and end-of-life care of people with diabetes: Issues, challenges and strategies.** The authors make the case for early initiation of palliative care (PC) and proactive planning for end of life. Early use of PC improves symptom management, comfort and quality of life, and often improves function. It reduces disease burden and unnecessary treatment. **Abstract (w. link to references):** https://goo.gl/wEJfNE

Specialist Publications

"Sacred pause" in the ICU: Evaluation of a ritual and intervention to lower distress and burnout

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 4 April 2018 – Increased exposure to deaths in the intensive care unit (ICU) generate grief among ICU staff, which remains unresolved most of the time. Unresolved grief becomes cumulative and presents a risk factor for burnout. "Sacred pause" is a ritual performed at patient's death to honor the lost life and recognize the efforts of the health-care team. Seventy-nine percent [of survey] respondents believed that the ritual brought closure and helped them overcome the feelings of disappointment, grief, distress, and failure after the death of their patient in ICU. Seventy-three percent agreed that the ritual has instilled and encouraged a sense of team effort. Eighty-two percent responded that the ritual makes their efforts feel appreciated. Many felt that the ritual should be a universal phenomenon in all ICUs. Only 55% respondents felt that the practice has a potential to decrease ICU burnout... **Abstract:** https://goo.gl/Lmwvyi

End-of-life care in Japan

Bereaved family members' perceptions of the distressing symptoms of terminal patients with cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 2 April 2018 – Few data are available on bereaved family members' perspective on the frequency of symptoms and degree of distress among terminal patients with cancer. The authors sent a questionnaire to 1,472 bereaved family members of terminal patients with cancer in 20 general hospitals. Anorexia was the commonest symptom among terminal patients with cancer experienced by bereaved family members [i.e., survey respondents], followed by somnolence, weight loss, fatigue, and pain. There are not means of effective treatment now. Further study in this field is necessary. **Abstract:** https://goo.gl/4SRpiF

Striving for a balance between leading and following the patient and family: Nurses' strategies to facilitate the transition from life-prolonging care to palliative care...

BMC PALLIATIVE CARE | Online – 3 April 2018 – Palliative care (PC) has changed during the last decades and today the patient and family are involved in the PC process in a much more direct way compared with previously. The patient's role has been strengthened, as the health care team are obliged to inform patients of their prognosis, be open for a discussion about any change in goals, and plan the care in line with the individual patient's wishes. The end of a person's life is often characterized by physiological, social and existential changes due to loss of roles and functions that effect self-image, often occurring in parallel with physical suffering. This situation is challenging, and the patient and their family need to be supported. However, knowledge of how to support the patient and family in this specific phase is lacking, and this needs to be further explored. **Full text:** https://goo.gl/fkGsJ7

End-of-life care in Canada

Access to palliative care by disease trajectory: A population-based cohort of Ontario decedents

BMJ OPEN | Online – 5 April 2018 – This study quantifies a large disparity in access to palliative care (PC) for those dying from organ failure and frailty trajectories. Decedents with a terminal illness trajectory, exemplified by a cancer diagnosis, are significantly more likely to receive PC services than the other dying trajectories; they receive more services (intensity) both in hospital and community, and these services are initiated earlier in the dying trajectory. All trajectories could benefit from increased access to palliative home care services and physician home visits. This data will be useful to compare to in the future since a national PC framework was an identified need and has recently been passed into law.[1,2] These data also serve as a useful comparison for other countries with similar and different healthcare systems and eligibility criteria to explore PC access across disease trajectories. **Full text:** https://goo.gl/duyQma

1. 'A national palliative care strategy for Canada,' *Journal of Palliative Medicine*, 2018;21(S1):S63-S75. [Noted in the 1 January 2018 issue of Media Watch (#544, p.18)] **Abstract:** https://goo.gl/r7C1HR

2. Bill C-277 received Royal Ascent 12 December 2017. [Noted in the 18 December 2017 issue of Media Watch (#543, pp.1-2)] **Download/view at:** https://goo.gl/LWW6kT

Palliative care in medical practice: Medical students' expectations

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 4 April 2018 – During their careers, all doctors will be involved in the care of the dying, and this is likely to increase with current demographic trends. Future doctors need to be well-prepared for this. Little is known about medical students' expectations about providing palliative care (PC). Fifteen U.K. medical schools participated in this study, with 1,898 first and final year students completing an online questionnaire which investigated how satisfying they expect providing PC to be and their attitudes towards PC. At both the beginning and end of their training, a significant proportion of students expect PC to be less satisfying than other care (19.3% first year, 16% final year). Students expecting PC to be less satisfying were more likely to be men, and their attitudes suggest that while they understand the importance of providing PC they are concerned about the potential impact of this kind of work on them personally. Medical student education needs to address why PC is important and how to deliver it effectively, and the strategies for dealing positively with the impact of this work on future clinicians. **Abstract:** https://goo.gl/dFvnRg

Later-life homelessness as disenfranchised grief

CANADIAN JOURNAL ON AGING | Online – 2 April 2018 – Findings [of this study] reveal that homelessness evoked a grief response characterized by shock, despair, anger, and in some cases, relief. Connecting and receiving support from other shelter residents and staff helped participants to acknowledge and grieve their losses. However, difficult shelter conditions, the stigma associated with aging and homelessness, and not having their grief recognized or validated served to disenfranchise grief experiences. Conceptualizing later-life homelessness as disenfranchised grief contributes to the aging and homelessness literature while providing new avenues for understanding and validating the experiences of a growing population of vulnerable older adults. **Abstract:** https://goo.gl/ePEc5x

N.B. Articles on palliative and end-of-life care for the homeless noted in the 12 and 26 February 2018 issues of Media Watch (#550, p.3 & p.7, and #552, p.2, respectively).

Parent perspectives of receiving early information about palliative and end-of-life care options from their child's pediatric providers

CANCER NURSING | Online – 3 April 2018 – The aim of this study was to describe parental perspectives about receiving an early palliative care and end-of-life (PC/EoL) communication intervention titled 'Communication Plan: Early through End-of-Life Intervention' (COMPLETE) from an interprofessional team of physician and registered nurse providers. Results included two theme categories: 1) COMPLETE nurtures realistic hope and meaningful dialogue by parents connecting with healthcare providers as a dyad; and, 2) Benefits of COMPLETE helped parents to make informed decisions. In addition, there were offered suggestions to improve COMPLETE. The COMPLETE intervention provided a unique mechanism to foster early discussions about PC/EoL options between parents and an interprofessional team during the first six months of the child's cancer treatment. **Abstract:** https://goo.gl/oGqyw9

Related

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 2 April 2018 – **'From fear to confidence: Changing providers' attitudes about pediatric palliative and hospice care.'** Few existing hospice programs have dedicated pediatric teams, and adult hospice providers feel inadequately trained to care for children. The aim of this study is to increase access to pediatric hospice care by empowering adult hospice providers to care for children through a comprehensive education program. **Abstract (w. link to references):** https://goo.gl/bZWQT8

Perhaps quality of life should not be used as a trigger for discussing resuscitation and advance care plans

EMERGENCY MEDICINE AUSTRALASIA | Online – 2 April 2018 – As a subjective measure, quality of life (QoL) should not be used as a trigger for discussing resuscitation, goals of care or advanced care plans. Limitations and challenges in measurement and assessment of QoL have been recognised. It is a fluid construct and subject to changes and response shifts. Surrogate QoL estimations may misrepresent individual worth and self-perceived QoL. Disagreement over QoL statements may cause harm. **Abstract:** https://goo.gl/ZTvPpR

The evolving moral landscape of palliative care

HEALTH AFFAIRS, 2018;37(4):670-673. Deactivating a patient's medical device provides a "good" death, which reflects how perspectives on hastening death have changed. **Abstract:** https://goo.gl/bkv7P2

The experiences and preparedness of family carers for best interest decision making of a relative living with advanced dementia: A qualitative study

JOURNAL OF ADVANCE NURSING | Online – 30 March 2018 – 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. The experiences and preparedness of informal carers is a reflection of their personal response, but the distress experienced highlights the significant need of adequate support availability and of enhancing nursing staffs' dementia expertise to maximise their role in facilitating best interest decision-making. This has significant implications for nursing practice and for service user and nursing staff education. Considering the global impact of dementia these findings have international relevance for similar nursing homes across the world. **Abstract:** https://goo.gl/8rMBBP

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Related

- *AGING & MENTAL HEALTH* | Online – 2 April 2018 – **'Exploring provider-surrogate communication during POLST discussions for individuals with advanced dementia.'** Study participants primarily focused on making sense of the clinical information about life-sustaining treatments during Physician Orders for Life-Sustaining Treatment (POLST) conversations. Providers demonstrated emotional support by valuing what the surrogate said, acknowledging the surrogate's emotions, listening carefully, understanding the patient as a person, and eliciting questions. However, providers rarely conveyed comprehensive information about the patient's current condition and end-of-life treatment options. **Abstract:** https://goo.gl/e733Xt

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 6 April 2018 – **'National standards and state variation in Physician Orders for Life-Sustaining Treatment forms.'** The National POLST Paradigm Task Force maintains consensus-based standards for POLST programs and uses these to determine whether a state POLST program is developing, endorsed or mature. There is variability in adherence to required and optional standards as well as challenges in interpreting and applying existing standards. Although there may be legal and logistical barriers to the existence of a national POLST form, standardization remains an important goal to support patient-centered care. **Abstract:** https://goo.gl/6oPpnj

Availability of Dutch general practitioners for after-hours palliative care

JOURNAL OF PALLIATIVE CARE | Online – 2 April 2018 – In The Netherlands, after-hours primary care for palliative patients is either provided by general practitioner (GP) cooperatives or GPs who choose to give palliative care (PC) by themselves while they are not on duty. Of the GPs [i.e., survey respondents], 60.8% were personally available outside office hours for their own palliative patients on their own private cell phone, and they performed home visits if needed. 33% of respondents were willing to make home visits in private time instigated by the GP cooperative and 26.8% were only accessible for telephone consultation by the GP cooperative. 12.2% of respondents delegated after-hours PC completely to the GP cooperative. GPs predominantly reported "time pressure" problems (17.3%) as a barrier and 61.7% stated that after-hours PC is the responsibility of the patient's own GP. **Full text:** https://goo.gl/zSSvX6

Ten tips nephrologists wish the palliative care team knew about caring for patients with kidney disease

JOURNAL OF PALLIATIVE MEDICINE | Online – 1 April 2018 – Many patients with chronic kidney disease (CKD) and end-stage renal disease have unmet palliative care (PC) needs. Physical and emotional symptoms are common. Some, like uremia and fluid overload, improve with dialysis, but the increasing age of patients initiating renal replacement therapy leaves many untreatable co-morbidities like dementia and frailty to negatively impact quality of life. Written by nephrologists and PC clinicians, this article will help PC providers to have a richer understanding of kidney disease-related symptom burden, disease trajectory, prognosis, and barriers to hospice enrollment for patients with CKD and end-stage renal disease. **Abstract:** https://goo.gl/ZETT6G

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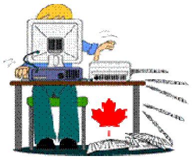

Barry R. Ashpole

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

Related

- *BMC PALLIATIVE CARE* | Online – 5 April 2018 – '**Health service utilisation during the last year of life: A prospective, longitudinal study of the pathways of patients with chronic kidney disease stages 3-5.**' Nephrology experts worldwide note that the quality of care, particularly conservative and palliative care, is currently sub-optimal for persons with advanced chronic kidney disease. It is therefore imperative to assemble timely, effective and sustainable high quality care pathways that meet patient need. **Full text:** https://goo.gl/pChejG

N.B. Additional articles on palliative care for people living with chronic kidney disease noted in the 12 March 2018 issue of Media Watch (#554, p.6).

Identifying the population with serious illness: The "denominator" challenge

JOURNAL OF PALLIATIVE MEDICINE, 2018;21(S2):S7-S16. Seriously ill people and their families are at risk of low quality and overly burdensome healthcare, and timely primary or specialist palliative care services may ameliorate this risk. An upstream and proactive approach to meeting the care needs of this vulnerable population requires a method of prospective identification. The primary impediments currently are the lack of a "gold standard" for identification of need and inadequate assessment measures in administrative data. The simulated approaches to defining the seriously ill denominator population described in this work offer high levels of specificity. Clinical programs may choose to focus on this highest-need segment of the seriously ill population and may indeed have the highest positive impact on care for this group now. **Full text:** https://goo.gl/46fgMf

N.B. The focus of this supplement to the *Journal of Palliative Medicine* is on quality measures for the care of the seriously ill. **Journal contents page:** https://goo.gl/mRQd17

The Buddy Group – peer support for the bereaved

LONDON JOURNAL OF PRIMARY CARE | Online – 28 March 2018 – The authors describe the story of the Buddy Groups for bereaved people that were set up at Weston Hospicecare [Weston-super-Mare, England] in 2008 and have endured ever since. The groups have helped bereaved people to find meaning and value despite their grief. The authors observed that, through the strength of the relationships formed, people were able to recover well. Group members reported the significant value they placed on being in a Buddy Group. Significant numbers of people suffer in silence, but at the same time do not require specialist bereavement care. **Full text:** https://goo.gl/PWrx5X

Adolescent decision-making in Canadian medical contexts: Integrating neuroscience and consent frameworks

PAEDIATRICS & CHILD HEALTH | Online – 7 April 2018 – This commentary draws on the Canadian health care system specifically to consider consent frameworks that grant young people with decision-making capacity. Next, a brief review of adolescent brain development findings is presented, particularly pertaining to the decision-making capacity of young people within medical contexts. Ultimately, the question of whether the stage of a young person's brain development impedes their capacity to consent to, or refuse medical treatment is addressed. This commentary provides reassurance as to the compatibility between capacity-based and mature minor frameworks to consent to treatment with current neuroscientific understanding of adolescent brain development. **Abstract:** https://goo.gl/cFFN22

Noted in Media Watch 16 January 2017 (#495, p.7):

- *THE HASTINGS REPORT* | Online – 11 January 2017 – '**Conflating capacity and authority: Why we're asking the wrong question in the adolescent decision-making debate.**' Using data from magnetic resonance imaging and functional MRI studies, authors have argued both that the adolescent brain isn't sufficiently mature to broadly confer capacity on this population and that the adolescent brain is sufficiently mature to assume adolescent capacity. Scholars then accept these data as sufficient for concluding that adolescents should or should not have decision-making authority. Two critical mistakes are being made here. **Abstract:** https://goo.gl/ciyAEi

How and when do patients request life-expectancy estimates? Evidence from hospice medical consultations and insights for practice

PATIENT EDUCATION & COUNSELING | Online – 2 April 2018 – Life-expectancy estimate episodes frequently begin after a doctor has given a patient an opportunity to shape the consultation agenda. Rather than posing direct questions, patients cautiously display their interest in receiving an estimate using statements. These often contain preparatory information about: what they already know about their prognosis, their perspective on it, and readiness to hear more. When patients do not provide this information, doctors [i.e., study participants] invite it before giving an estimate. Patients' companions also contribute to this preparatory work. Doctors, patients, and companions collaboratively work to prepare a conversational environment wherein emotional states and uncertainties have been addressed prior to delivery of the actual estimate. This helps manage both possible emotional distress, and prognostic uncertainty entailed in seeking and delivering estimates. **Abstract:** https://goo.gl/g3B4mi

Related

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 2 April 2018 – **'Surrogate decision makers' perspectives on family members' prognosis after intracerebral hemorrhage.'** 19% of study participants reported receiving discordant prognoses, leading to distress or frustration in 15% of cases and a change in decision for potentially life-saving brain surgery in 6% of cases. Surrogates were surprised or confused by providers' use of varied terminology for diagnosis ... and reported that physicians expressed uncertainty in prognosis in 37% of cases. **Abstract:** https://goo.gl/xrYqsJ

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC PALLIATIVE CARE* | Online – 4 March 2018 – **'Exploring attitudes toward physician-assisted death in patients with life-limiting illnesses with varying experiences of palliative care: A pilot study.'** This study suggests terminally ill patients with and without palliative care (PC) equally support the provision of physician assisted death (PAD) and report hypothetical considerations of PAD that increase over time. A trend emerged that suggests patients with prior and ongoing PC and new palliative consultation are more likely to consider PAD for themselves in the future than patients without palliative involvement. Despite a widely supported call for a national PC strategy, the delivery of PC continues to be a challenge in Canada, given the aging population, the increasing burden of chronic diseases, the scarcity of resources, and the evolving expectations of the population. **Abstract:** https://goo.gl/w9CSyk

- *HEALTH PROMOTION INTERNATIONAL*, 2018;33(2):183-186. **'Healthy dying: Time for health promotion to get serious.'** Encouragingly, legalization of physician-assisted death appears to have contributed to improvements in palliative care (PC). In Oregon, improvements have occurred in training of physicians, patient communication, pain management, and referral to hospice programs – and deaths occurring at home... In Belgium, the process of legalization together with development of PC can be mutually reinforcing... However, the European Association for Palliative Care asserts that euthanasia is not a part of PC ... and that legislation should not require doctors to be the gate keeper in assisted suicide... **Full text:** https://goo.gl/LvKCxU

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

Cont.

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6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

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

Media Watch: Access on Online

Updated 03.31.2018

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/38NX5H

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

PALLIATIVE CARE NETWORK-e: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at https://goo.gl/6vdk9v]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/ZRngsv

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

Australia

PALLIATIVE CARE WESTERN AUSTRALIA: https://goo.gl/fCzNTL

[Scroll down to 'International Websites']

Canada

BRITISH COLUMBIA HOSPICE PALLIATIVE CARE ASSOCIATION: https://goo.gl/qw5ti8

[Click on 'National Resources,' scroll down to 'Palliative Care Network Community']

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CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2

[Scroll down to ‘Are you aware of Media Watch?’]

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD

[Scroll down to ‘Additional Resources’]

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): https://goo.gl/lOSNC7

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC

[Scroll down to ‘International Palliative Care Resource Center hosts Media Watch’]

SASKATCHEWAN | Saskatchewan Medical Association: https://goo.gl/5cftPV

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Europe

EUROPEAN JOURNAL OF PALLIATIVE CARE: https://goo.gl/jjCHez

[January/February 2018 issue (Scroll down to ‘Paediatric palliative care; the patient’s voice’]

HUNGARY | Magyar Hospice Alapítvány: https://goo.gl/3jnH7K

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

South America

Academia Nacional de Cuidados Paliativos (Brazil): https://goo.gl/b5CV31

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