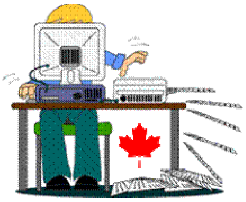
Media Watch... *is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.*

24 June 2019 Edition | Issue #619



Compiled & Annotated by Barry R. Ashpole

> *The authors' findings challenge the prevalent discourse that home is an inherently better place to receive end-of-life care than hospital and highlight the dissonance between policy rhetoric and the everyday reality of caring for patients close to the end of life.*
>
> 'Home care and end-of-life hospital admissions: A retrospective interview study in English primary and secondary care' (p.6), in *British Journal of General Practice.*

Canada

Many factors influence decisions to withdraw life support to brain injury patients: Study

YAHOO NEWS | Online – 17 June 2019 – There are several factors that determine the decisions to withdraw life support treatments in critically ill patients with severe brain injury, says a recent study.[1] The study … provides a new understanding of the decision-making processes for this patient population... Dr. Alexis Turgeon [at the Université Laval Research Centre] said: "Many clinicians struggle to make recommendations to withdraw life-sustaining treatments because decision-making is often complicated by uncertainty from trying to match family or caregiver opinions about what they think the patient would have wanted in terms of quality of life (QoL) and how well physicians can predict a prognosis." The death rate in critically ill patients with severe traumatic brain injury is generally high as it occurs after a decision to withdraw life-sustaining treatments. This patient population differs from the general intensive care unit (ICU) population as most patients were healthy before admission to the ICU, as compared with older patients who may already have a poorer QoL due to pre-existing illness. Several factors are accountable including the patients' pre-expressed wishes and the family's wishes, severity, and location of the injury, along with evidence. Past physician experience, legislation, opinions of colleagues and time are additional factors influencing decisions. The incidence of withdrawal of life-sustaining treatments and of death in critically ill patients with traumatic brain injury varies between hospitals. http://bit.ly/2Xm9iw3

Specialist Publications

'"If you understand you cope better with it": The role of education in building palliative care capacity in four First Nations communities in Canada' (p.6), in *BMC Public Health.*

'The impact of socio-economic status on place of death among patients receiving home palliative care in Toronto, Canada: A retrospective cohort study' (p.9), in *Journal of Palliative Care.*

Cont.

1. ‘Factors influencing decisions by critical care physicians to withdraw life-sustaining treatments in critically ill adult patients with severe traumatic brain injury,’ *Canadian Medical Association Journal*, published online 17 June 2019. **Full text:** http://bit.ly/2XZvk4M

U.S.A.

If doctor decides, aggressive end-of-life care more likely

FUTURITY: RESEARCH NEWS | Online – 19 June 2019 – Terminally ill patients who request that physicians make decisions on their behalf are more likely to receive aggressive treatments in the weeks before they die, a new study reports.[1] Further, the findings call attention to the fact that patients may accept aggressive treatments and highlight the need for better education about end-of-life care. “Some physicians are very comfortable taking over the decision-making for their terminally ill patients,” says lead author Paul Duberstein, chair of the health behavior, society, and policy department at Rutgers School of Public Health. “An important and surprising finding is that when physicians do take charge of treatment decisions, patients are more likely to receive aggressive interventions at the end of life. As a result, patients end up in intensive care units or emergency rooms in the days before death, even though most people would rather die peacefully at home.” The researchers examined chemotherapy use and hospitalizations or emergency department visits in the last 30 days of life of 265 patients who 38 oncologists cared for. They found that patients of physicians comfortable with offering aggressive medical interventions more likely received chemotherapy and endured difficult hospitalizations in the days and weeks before dying. Patients who had unfavorable attitudes toward palliative care and those who wanted to try medically unproven cancer treatments were also more likely to receive aggressive interventions. http://bit.ly/2IqE9PN

Specialist Publications

‘A tripartite model of community attitudes to palliative care’ (p.5), in *American Journal of Hospice & Palliative Medicine*.

1. ‘Physician and patient characteristics associated with more intensive end-of-life care,’ *Journal of Pain & Symptom Management*, published online 17 April 2019. **Abstract (w. link to references):** http://bit.ly/2N8ceZs

U.S. needs national strategy for palliative care

HOSPICE NEWS | Online – 19 June 2019 – The federal government should work with stakeholders to develop a national strategy for palliative care (PC), similar to those developed to combat smoking, H.I.V., the opioid epidemic and pandemic influenza, according to Diane Meier, M.D., director of the Center to Advance Palliative Care. A national strategy would bring together government agencies, health care organizations, the private sector and other stakeholders to develop a multifaceted plan to improve the state of PC in the U.S., addressing issues such as public awareness of and access to PC, addressing staff shortages, establishing payment models, and expanding utilization. A lack of public awareness is a significant barrier to expanding the use of PC in the U.S. A recent study found that 71% of people in the U.S. do not know what PC is.[1] http://bit.ly/2ZG8UpP

1. ‘Awareness of palliative care among a nationally representative sample of U.S. adults,’ *Journal of Palliative Medicine*, published online 30 April 2019. [Noted in 6 May 2019 issue of Media Watch (#613, p.9).] **Abstract:** http://bit.ly/2UT2Ozi

Share this issue of Media Watch with a colleague

New report urges congregations to aid family caregivers

RELIGION NEWS SERVICE | Online – 18 June 2019 – A new report on family caregivers details how congregations can play a role in supporting the increasing number of members caring for elders.[1] "Whether their care journey feels like a roller coaster, the deep end, or a long marathon, family caregivers are at risk of emotional, financial, and spiritual exhaustion as they balance both work and care and are tempted, often by necessity, to journey alone," writes the report's author, Lutheran pastor Amy Ziettlow. The report focused on civic education and policy research, proposes ways houses of worship, employers and the government can assist caregivers. http://bit.ly/31IBf0y

1. 'Called to Care: Honoring Elders & the Family Care Journey," Center for Public Justice, Washington DC, June 2019. **Download/view at:** http://bit.ly/2Rsi0na

International

Children's hospices "to shut if National Health Service does not increase funding"

U.K (England) | BBC News – 19 June 2019 – Children's hospices in England will be forced to cut services or shut unless the National Health Service (NHS) increases its funding, a charity has warned. Together for Short Lives, which helps terminally ill children, highlighted a "dangerous cocktail" of higher costs and a drop in state funding. Its report examined funding for 27 of the 34 children's hospices in England.[1] But NHS England said funding for children's end-of-life care was "going up every year." According to Together for Short Lives, children's hospices in England each spend an average of £3.7 million per year – which works out as a total annual spend across the country of £125 million. Their spending has increased by 4.5% since 2016-2017, it said. But the percentage which the state contributes has fallen from 27% to 21% in five years, the report said – and hospices have been forced to use their reserve funds or stop services. https://bbc.in/2WVIu6s

1. 'Statutory Funding for Children's Hospice and Palliative Care Charities in England, 2018-2019,' Together for Short Lives, June 2019. **Download/view at:** http://bit.ly/2FlGoSu

N.B. Recent news media coverage on funding issues impacting children's hospices in England noted in 17 June 2019 issue of Media Watch (#618, p.5).

End-of-life care in Australia

All Victorians can die with dignity, if they plan for it: Deakin researchers

AUSTRALIA (Victoria) | *Mirage News* (Wollongong, New South Wales) – 18 June 2019 – As voluntary assisted dying comes into effect this week, Deakin University end-of-life care experts believe a different existing law will have a much wider impact on promoting dignity in death for Victorians. Health law expert and Associate Professor at Deakin Law School Neera Bhatia said it was important to emphasise that voluntary assisted dying would only be available to, and accessed by, a very limited few.[1] "There may be an initial surge in interest however due to the strict criteria it will not accessible to many," Associate Professor Bhatia said. "But there is another piece of important legislation that ensures the wishes of all Victorians can be respected at the end of their lives." The Medical Treatment Planning & Decisions Act 2016, which quietly came into effect in Victoria last year, allows people to make an advance care directive outlining their future medical wishes and treatment preferences.[2] Bhatia said it offered a legally binding way for people to refuse or consent to specific treatments, including those that prolonged their life, something that could previously be overruled once a person was deemed to lack mental capacity. http://bit.ly/2IR3HEM

1. Voluntary Assisted Dying Act (2017): http://bit.ly/31xz6V8

2. Medical Treatment Planning & Decisions Act (2016): http://bit.ly/2IosyR5

Schools "need support of government to help grieving children"

U.K. | *The Guardian* (London) – 18 June 2019 – There is no government-led national bereavement policy for schools despite the equivalent of every classroom in the U.K. containing at least one child who has lost a parent or sibling, according to a report into the consequences of childhood bereavement in the British school system.[1] The report … found that more than 41,000 children under 18 in the U.K. lose a parent every year. When deaths of siblings are included, that number increases to at least 45,000 every year. "Childhood bereavement is a huge social issue that can lead to serious long-term consequences for not only the individual but for wider society and – ultimately – the economy," said Prof Colleen McLaughlin, the director of educational innovation at Cambridge University. "It is therefore a huge issue that there is currently no government-led national bereavement policy in place for schools – where bereaved children spend most of their waking hours." http://bit.ly/2XmciZd

Crossroads of Grief Project –
Grieving or Bereaved Children:
Literature Review (2015-2018)

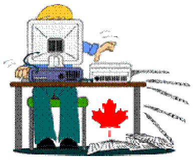
The Children & Youth Grief Network of Peel Region (Ontario, Canada) recently published a review of the literature focused on the many different aspects of grief and bereavement among children and young people. The main focus is on evidence-based studies published in peer-reviewed journals, reflecting current thinking on the many issues identified. **Download/view at:** http://bit.ly/2QZBaAs

1. 'Consequences of Childhood Bereavement in the Context of the British School System,' Cambridge University, June 2019. **Download/view at:** http://bit.ly/2WR9vD4

N.B. Researchers at Cambridge University also gathered the experiences of adults who lost parents and siblings as children. 'Voices of adults bereaved as children' reinforces the message that meaningful support is important in the aftermath of bereavement and that schools are key in providing it. **Download/view at:** http://bit.ly/2WR9vD4

U.K.'s Universal Credit: Number of terminally ill people forced to claim benefit revealed

U.K. | *HuffPost UK* – 17 June 2019 – More than 17,000 people with terminal illnesses have been forced to apply for benefits through the government's Universal Credit system, raising fears gravely sick people are resorting to food banks or dying before vital payments arrive. The figures, obtained exclusively by *HuffPost UK*, show the sheer number of people having to navigate the government's complex new welfare system when they are facing the end of their lives. The data, released by the Department of Work & Pensions (DWP) under a Freedom of Information request, shows 17,000 people answered "yes" when asked: "Have you been diagnosed with a terminal illness" on the digital application form between 2016 and 2018. Of the almost 2.2 million who applied for Universal Credit online in the same period, 31,000 also ticked a box saying "Please call me to discuss terminal illness" in a section asking if they required a call-back from the DWP. Charities have called for an urgent reform of the system, saying thousands of terminally ill people could be missing out on crucial funds. http://bit.ly/2XnDIy2



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://bit.ly/2RPJy9b

Death in people aged 75 years and older in England in 2017

U.K. (England) | Public Health England – 14 June 2019 – Approximately half a million people die in England each year, two-thirds of whom are aged 75 years of age and older. Life expectancy has risen over the past 25 years and, as such, the fraction of people aged 75 years and older has risen and is projected to continue to rise. As a result, the number of deaths in this age group is rising at an accelerated rate. The population of England is ageing, and this has important implications for the provision of end-of-life care… This report considers differences in the causes of death and places of death amongst people aged 75 years and older in England in 2017 and examines how these differences have changed over the past decade. The influence of factors such as age, sex and socioeconomic deprivation on cause and place of death are investigated. **Download/view at:** http://bit.ly/2RjiMTc

Extract from Public Health England report

Since 2007, the proportion of deaths in hospital has fallen. Deaths at home and in care homes have become more common, and deaths in hospices have become slightly more common since 2007.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | Palliative Care Australia – 20 June 2019 – **'Voluntary Assisted Dying: Guiding principles for those providing care to people living with a life-limiting illness.'** The association has published a set of seven principles, which guide health professionals providing care to people living with a life-limiting illness as part of the Victorian Voluntary Assisted Dying scheme. 'Voluntary Assisted Dying in Australia: Guiding principles for those providing care to people living with a life-limiting illness' is national in scope and designed to sit alongside enacted state legislation where it exists, organisational ethical frameworks and professional codes of conduct. **Download/view at:** http://bit.ly/2N2eLEo

Specialist Publications

A tripartite model of community attitudes to palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 20 June 2019 – Despite a growth in palliative care (PC) services, access and referral patterns are inconsistent and only a minority of people who would benefit from such care receive it. Use of PC is also affected by community attitudes toward PC. As such, determining community attitudes toward PC is crucial. There is also a need to determine what predicts attitudes in order to provide appropriate information and education. The average attitude and belief responses [to a survey] were very positive, the average emotions responses were somewhat positive. The sample had good knowledge of PC. Lowest knowledge scores were reported for the items: "euthanasia is not part of palliative care," "PC does not prolong or shorten life," and "specialist PC is only available in hospitals." It was found that beliefs, emotions, and knowledge each accounted for a significant proportion of unique variance in attitude toward PC. Each variable had a positive relationship with attitude. **Abstract:** http://bit.ly/2LbVltU

“If you understand you cope better with it”: The role of education in building palliative care capacity in four First Nations communities in Canada

BMC PUBLIC HEALTH | Online – 17 June 2019 – In Canada, there is a growing need to develop community-based, culturally appropriate palliative care (PC) for Indigenous people living in First Nations communities. With an emphasis on social and community care, the public health approach to PC is relevant. The research presented here offers an example of the public health approach in four First Nations communities in Canada, and offers implementation strategies around PC education (a key strategy in the public health approach). The emphasis was on community capacity building through education; the focus was on identifying needs and presenting solutions. Implementation strategies are offered around assessing educational needs and addressing them. The authors’ hope is that the community assessment methodology, case study of educational needs, and the examples of resources and strategies for addressing those needs presented here will be helpful for those looking to develop PC programs and capacity in Indigenous communities in Canada and internationally. **Full text:** http://bit.ly/2WSbhsn

N.B. Additional articles on PC for the Indigenous peoples of Canada noted in 22 April 2019 issue of Media Watch (#611, p.5).

Home care and end-of-life hospital admissions: A retrospective interview study in English primary and secondary care

BRITISH JOURNAL OF GENERAL PRACTICE | Online – 17 June 2019 – The authors’ findings challenge the prevalent discourse that home is an inherently better place to receive end-of-life (EoL) care than hospital and highlight the dissonance between policy rhetoric and the everyday reality of caring for patients close to the EoL. The present research suggests if policy and practice maintain an emphasis on facilitating deaths at home, there must also be a concurrent focus on ensuring patients can die there safely. Identifying how best to achieve this will require further research, and is likely to require investment to ensure community nursing provision is adequately staffed, responsive, and available throughout the day and night. Supplementing this essential provision with rapid and reliable specialist clinical services that offer support for patients at home for extended periods of time, such as hospice at home and Marie Curie nursing services, would also be pertinent. To facilitate care delivery, primary care clinicians must be supported by adequate information-sharing practices, and be confident in delivering palliative and EoL care. Family carers must also be supported, including greater recognition of their needs. Pejorative assessments of the association between family care and EoL hospital admissions obscures the significant undertaking of lay carers to support patients at home. Future research could productively address how families persist in providing care, and how GPs and others can best support them. **Full text:** http://bit.ly/2ZzhxSG

Noted in Media Watch 16 November 2015 (#436, p.18):

- *PLOS ONE* | Online – 10 November 2015 – **‘Do patients want to die at home? A systematic review of the U.K. literature, focused on missing preferences for place of death.’** It is unknown what proportion of U.K. patients prefers to die at home. The authors found no clear difference between preferences for home and the diagnosis of patients. Ultimately, preferences for place of death appear to depend on who is asked the question; what, where, why and when they are asked, and how those without an answer are included. **Full text:** http://bit.ly/2WZAhya

Time is Precious Project

Person-centred end of life care in an emergency department. A quality improvement project

EMERGENCY NURSE | Online – 18 June 2019 – Supporting and managing end of life (EoL) in emergency departments (EDs) is often difficult and is becoming increasingly commonplace. Patients who present at the EoL are often triaged as low priority as their signs and symptoms are not considered life-threatening and they are often exposed to unnecessary and inappropriate tests and investigations. This

Cont.

results in increased stress and distress for patients and their family and carers in an environment that is not suited to this type of care. There are few specified palliative care (PC) pathways that provide the level of care required by these patients. This article describes the Time is Precious (TiP) Project, the development of a PC decision-making framework to support and address the needs of patients who present to an ED at EoL, in a timely and appropriate manner. It also reports findings of an evaluation of TiP that show patients are identified more quickly and cared for more appropriately as nursing and medical care can be tailored to meet their needs. **Abstract:** http://bit.ly/2RIKNcU

The Second Conversation Project: Improving training in end-of-life care communication among junior doctors

FUTURE HEALTHCARE JOURNAL, 2019;6(2):129-136. The Second Conversation Project was designed by a multi-professional steering group as a workplace based training intervention for junior doctors [in the U.K.] to improve their skills and confidence in undertaking end-of-life care (EoLC) conversations. This is a three-step training intervention that involves 1) Observation – the junior doctor observes an EoLC conversation between a senior doctor and patient/caregiver; 2) Direct experience – the junior doctor undertakes a follow-up second conversation with the patient/caregiver; and, 3) Reflection – the junior doctor discusses and reflects on the experience with a senior colleague. Interviews were analysed using framework analysis and findings informed iterative changes to the intervention and its implementation using 'Plan, Do, Study, Act' cycles. Benefits that were identified included the flexibility of the intervention and its positive impact on the confidence and skills of junior doctors. The Second Conversation Project was felt to be of most value to newly qualified doctors and worked well on wards where length of stay was longer and EoLC conversations frequently happen. **Full text:** http://bit.ly/2IqdP8t

End-of-life care in Taiwan

The impact of health literacy on knowledge, attitude and decision towards hospice care among community-dwelling seniors

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 18 June 2019 – This cross-sectional study enrolled 990 community-dwelling elderly participants in three residential areas... Health literacy was assessed using the Mandarin version of the European Health Literacy Survey Questionnaire. More than half of the respondents had sufficient knowledge of hospice care (60.7%) and a positive attitude (77.3%) and positive decision (85%) towards hospice care. In the structural equation model, general health literacy positively predicted knowledge, attitude and decision towards hospice care. General health literacy had a greater overall effect on hospice decision than hospice knowledge. In addition, disease prevention health literacy also demonstrated a higher level of influence on hospice decision than hospice knowledge. **Abstract:** http://bit.ly/2x0rSeq

Palliative opioid use, palliative sedation and euthanasia: Reaffirming the distinction

JOURNAL OF MEDICAL ETHICS | Online – 20 June 2019 – *We read with interest the extended essay published from Riisfeldt and are encouraged by an empirical ethics article which attempts to ground theory and its claims in the real world. However, such attempts also have real-world consequences. We are concerned to read the paper's conclusion that clinical evidence weakens the distinction between euthanasia and normal palliative care (PC) prescribing. This is important. Globally, the most significant barrier to adequate symptom control in people with life-limiting illness is poor access to opioid analgesia. Opiophobia makes clinicians reluctant to prescribe and their patients reluctant to take opioids that might provide significant improvements in quality of life. We argue that the evidence base for the safety of opioid prescribing is broader than that presented, restricting the search to PC literature produces significant bias as safety experience and literature for opioids and sedatives exists in many fields. This is not acknowledged in the synthesis presented. By considering additional evidence, we reject the need for agnosticism and reaffirm that palliative opioid prescribing is safe. Second, palliative sedation in a clinical context*

Cont.

is a poorly defined concept covering multiple interventions and treatment intentions. We detail these and show that continuous deep palliative sedation (CDPS) is a specific practice that remains controversial globally and is not considered routine practice. Rejecting agnosticism towards opioids and excluding CDPS from the definition of routine care allows the rejection of Riisfeldt's headline conclusion. On these grounds, we reaffirm the important distinction between PC prescribing and euthanasia in practice. **Abstract:** http://bit.ly/2L8eFbv

> **N.B.** Access the article by Riisfeldt, 'Weakening the ethical distinction between euthanasia, palliative opioid use and palliative sedation,' and other reader responses at: http://bit.ly/2LeH5AC. Additional articles on palliative or terminal sedation noted in 29 April 2019 issue of Media Watch (#612, p.7).

Toward understanding the relationship between prioritized values and preferences for cardiopulmonary resuscitation among seriously ill adults

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 19 June 2019 – Prioritizing amongst potentially conflicting end-of-life values may help patients discriminate amongst treatments and allow clinicians to align treatments with values. Of 535 patients [i.e., survey respondents], 60% prioritized relief of discomfort over extending life, 17% prioritized extending life over relief of discomfort, and 23% were unsure. Patients prioritizing extending life were most likely to prefer CPR, with 93% preferring CPR in current health and 67% preferring CPR if dependent on others, compared to 69% and 21% respectively for patients prioritizing relief of discomfort, and 78% and 33% respectively for patients unsure of their prioritized value. Among patients prioritizing relief of discomfort, preference for CPR in current health was less likely among older patients and more likely with better self-perceived health. Clinicians face challenges as they clarify patient values and align treatments with values. Patients' values predicted CPR preferences, but a substantial proportion of patients expressed CPR preferences that appeared potentially inconsistent with their primary value. Clinicians should question assumptions about relationships between values and CPR preferences. **Abstract (w. link to references):** http://bit.ly/2Rux4AD

Development of a pediatric palliative care curriculum and dissemination model: Education in Palliative & End-of-Life Care (EPEC) pediatrics

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 17 June 2019 – Most children living and dying with serious illnesses experience high burden of distressing symptoms. Many seriously ill children and their families do not have access to subspecialist pediatric palliative care (PPC) services nor to clinicians trained in primary PPC. Lack of PPC education appears to be a significant barrier to PPC implementation. This 24-module curriculum was designed to teach primary palliative care. The target audience included interprofessional pediatric hematology/oncology providers and all other clinicians caring for seriously ill children. The curriculum is delivered in a combination of online learning and in-person, face-to-face sessions. Additionally, a one-day Professional Development Workshop (PDW) was developed to teach EPEC-Pediatrics graduates to teach future "Trainers," thus becoming "Master Facilitators." Between 2012-2019 a total of 867 EPEC-Pediatric Trainers and 75 Master Facilitators from 58 countries participated in 17 Become an EPEC-Pediatrics-Trainer conferences and three PDWs. The curriculum has also been adapted for large-scale dissemination across Canada and Latin-America, with translation to French and Spanish. Participants overwhelmingly report improvements in their PPC knowledge, attitudes, and skills, including teaching. Participants subsequently anticipated improvements in patient care for children with serious illness at their home institutions. **Abstract (w. link to references):** http://bit.ly/31F5ipF

Narrative interventions in the palliative care setting: A scoping review

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 16 June 2019 – A scoping review was performed to address the research question: What observational or randomized controlled trials have been performed to evaluate narrative interventions in the palliative care (PC) setting? The authors identified 34 articles for inclusion. Narrative interventions have focused on reflection or communication, and have been studied among providers, students, patients, and caregivers. Only patient/caregiver studies utilized randomized controlled design. Most were small and at the level of evaluating feasibility. Challenges include a high degree of heterogeneity among interventions, as well as heterogeneity among parameters for evaluating those interventions. Narrative interventions are actively being evaluated with the intention of improving communication and wellbeing among all parties within the PC and end-of-life experience. The field would benefit from selecting a subset of outcomes that are comparable across studies, and a common framework for describing narrative interventions. Scant literature exists regarding narrative interventions to assist providers in communication. **Abstract (w. link to references):** http://bit.ly/2wVhQLA

The impact of socio-economic status on place of death among patients receiving home palliative care in Toronto, Canada: A retrospective cohort study

JOURNAL OF PALLIATIVE CARE | Online – 16 June 2019 – Socio-economic disparities in home death have been noted in the literature. Home-based palliative care (PC) increases access to home death and has been suggested as a means to decrease these disparities. This is a retrospective chart review of patients who died between August 2013 and August 2015 when admitted to a home-based PC service. A total of 2,066 patients were included... Those in the lowest income quintile had increased odds of dying in acute care or dying in the PC unit than patients in highest income quintile. Patients in the next lowest income quintiles … were also more likely to die in acute care. The rate of preference for home death was significantly lower in the lowest income quintile. **Abstract:** http://bit.ly/2WOtZRY

Noted in Media Watch 17 June 2019 (#618, p.12):

- *PALLIATIVE MEDICINE* | Online – 12 June 2019 – **'What socio-economic factors determine place of death for people with life-limiting illness? A systematic review and appraisal of methodological rigour.'** Dying at home was to a high degree associated with better financial situation and living in rural areas. Furthermore, hospital death was associated with a high level of deprivation in the area of residence and being employed. Inequalities concerning place of death were found, and attention towards socio-economic inequality concerning place of death is necessary, especially in patients with a poor financial status, patients living in deprived and metropolitan areas and patients who are employed. **Abstract:** http://bit.ly/2R7zlS4

Do we know what we mean? An examination of the use of the phrase "goals of care" in the literature

JOURNAL OF PALLIATIVE MEDICINE | Online – 19 June 2019 – There is no consensus approach to describe the process or components of goals of care (GoC) conversations. A total of 191 articles were reviewed after exclusions. Few articles included an operant definition for GoC. It was often used to describe conversations focused on determining intent for treatment, talks about death or dying, or simply vague discussions. The agenda was focused on the outcomes of the conversation compared with factors such as hopes, worries, values, and personhood. The majority did not utilize the phrase "palliative care"; those who did frequently used "palliative care" incorrectly. The definition of the phrase GoC is most often assumed with its context centered on the needs of the health care system and linked to a specific medical topic. It is most commonly used to describe determinations of the patient's therapy intent, second most commonly to describe end-of-life conversations. The use of the phrase GoC within the palliative literature does not differ notably from its use in the broader literature. **Abstract:** http://bit.ly/2FoKKsd

Would this article be of interest to a colleague?

Utilization of advance care planning for homeless adults: Case studies

JOURNAL OF URBAN HEALTH | Online – 7 June 2019 – Given the barriers to advance care planning (ACP) and low utilization of outpatient advance directives in hospital settings, it is unclear if ACP in primary care for adults who have experienced homelessness is effective and a valuable use of clinical time. As part of the authors' ACP project, they examined the feasibility and outcomes of ACP in primary care for patients who have experienced homelessness. The authors found that such efforts had significant impacts on patients' hospital care and allowed their wishes to be honored when they lost capacity for medical decision-making, particularly at the end of life. They present six case studies demonstrating the outcomes of ACP in primary care for homeless adults and highlight lessons learned. To their knowledge, this is the first case series showing how ACP for homeless adults in primary care has been utilized during hospital care. **Abstract (w. list of references):** http://bit.ly/2WOeaWe

Care For the Homeless

> **N.B.** Additional articles on hospice and end-of-life care for the homeless in the U.S. noted in 7 January 2019 issue of Media Watch (#596, p.3).

How and how much is spirituality discussed in palliative care consultations for advanced cancer patients with and without a question prompt list?

PATIENT EDUCATION & COUNSELING | Online – 19 June 2019 – Patients want to discuss spirituality more with their doctors but feel disempowered. Question prompt lists (QPLs) assist conversations. This was a sub-study of a trial in which palliative care (PC) patients were randomised to either receive a QPL prior to a consultation or not, to see whether its provision influenced advanced cancer patients'/ caregivers' questions and discussion of topics relevant to end-of-life care during consultations with a PC physician. 174 patients participated. Spirituality was discussed in half the consultations. Patients receiving a QPL discussed spirituality 1.38 times more than controls. This finding did not reach statistical significance. First PC consultation and being asked about their concerns by the doctor were significant predictors of a spiritual discussion. **Abstract:** http://bit.ly/2Ku6JSr

Noted in Media Watch 10 June 2019 (#617, p.5):

- *AMA JOURNAL OF ETHICS*, 2019;21(6):E485-E492. **'How should physicians respond to patient requests for religious concordance?'** In which ways and in which circumstances should institutions and individual physicians facilitate patient-physician religious concordance when requested by a patient? This question suggests not only uncertainty about the relevance of particular traits to physicians' professional roles but also that medical practice can be construed as primarily bureaucratic and technological. This construal is misleading. Using the metaphor of shared language, this article contends that patient-physician concordance is always a question of degree and that greater concordance can, in certain circumstances, help to obtain important goals of medicine. **Full text:** http://bit.ly/2JSClvf

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

- *CANCER* | Online – 2 March 2019 – **'A scale to assess religious beliefs in end-of-life medical care.'** In this study the authors introduce and evaluate the Religious Beliefs in End-of-Life Medical Care scale, a new measure designed to assess religious beliefs within the context of end-of-life (EoL) cancer care. The scale has proved to be internally consistent, unidimensional, positively associated with other indicators of patients' religiousness and spirituality, and inversely associated with patients' terminal illness understanding and acceptance, suggesting its potential clinical usefulness in promoting informed EoL decision making. **Abstract:** http://bit.ly/2ITgxFF

> **N.B.** Additional articles on religious and spiritual beliefs in the context of EoL care noted in this issue of Media Watch.

Things that matter: Adolescent and young adult patients' priorities during cancer care

PEDIATRIC BLOOD & CANCER | Online – 17 June 2019 – Adolescents and young adults (AYAs) experience cancer while balancing emerging identity and life goals. The authors investigated AYAs' priorities during cancer, including psychosocial concerns, cure-directed therapy, and potential late effects. Patients' three most frequent priorities were cure (97%), being good to the people they care about (95%), and having supportive people around them (94%). Most prioritized being with family (90%), returning to school/work (89%), maintaining relationships with friends (88%), and feeling normal (85%). Fewer prioritized minimizing long-term (78%) and acute side effects (68%) and fertility (59%). Many participants (88%) said that cure influenced their decisions "a great deal," while fewer were influenced by side effects (32%), fertility (36%), or relationships (16%). Most patients (85%) thought their oncologist understood what was most important to them when treatment started. Nearly all AYA cancer patients prioritize cure, while maintaining social relationships and a sense of normalcy. These priorities influence decisions they make about treatment to differing degrees, with cure influencing decision-making for most patients. Although the priority of cure is well established, recognizing other AYA priorities allows providers to optimally support these patients from the time of diagnosis. **Abstract:** http://bit.ly/2KWqstz

When a child dies in the PICU

Practice recommendations from a qualitative study of bereaved parents

PEDIATRIC CRITICAL CARE MEDICINE | Online – 14 June 2019 – Bereaved parents identified several areas for care delivery and improvement across three time periods: during hospitalization; during the dying phase; and during bereavement. During hospitalization, parents' recommendations focused on improved communication, changes to the physical environment, better self-care resources, and provision of family support. During the dying phase, parents suggested private, demedicalized rooms, familiar staff members, and support to leave the hospital. Recommendations for care after death focused mainly on the provision of ongoing support from the hospital or local bereavement services, as well as improved information delivery. Findings from this study offer many concrete recommendations for improvements in care both during and after a child's death. These recommendations range from simple practice changes to larger organizational modifications, offering many potential avenues for change and improvement both on an individual healthcare provider level and within individual PICUs. **Abstract:** http://bit.ly/2Ko5MuV

Related

- *ACTA PAEDIATRICA* | Online – 17 June 2019 – **'Physicians working in oncology identified challenges and factors that facilitated communication with families when children could not be cured.'** Physicians from the six cancer centres in Sweden took part in focus group discussions. They reported communication challenges when a cure was not possible, namely: emotional and mental drain, lack of mutual understanding, and uncertainty about communication skills. They also reported facilitating factors: flexibility in complex conversations, the child's position in the conversations, continuity and trusting relationships, support from colleagues and having discussed the potentially life-threatening nature of cancer from the very start of treatment. **Abstract:** http://bit.ly/31EBauG

- *BRITISH MEDICAL BULLETIN*, 2019;130(1):81-88. **'Hospices and palliative care for children: Converging stories.'** Children's palliative care (PC) generally is poorly developed compared with the adult specialty, and local providers should work with hospices to help redress the inequity that children face in accessing specialist PC. If hospices are to continue to be important providers of PC in children they must develop robust and fair relationships with local healthcare providers. That would be facilitated by development of a funding formula for children that properly acknowledges the part hospices already play in PC. **Abstract:** http://bit.ly/2XnC7IB

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.13.

Reciprocity, autonomy, and vulnerability in men's experiences of informal cancer care

QUALITATIVE HEALTH RESEARCH | Online – 19 June 2019 – Men are increasingly participating, and acknowledging their roles, as informal carers. Yet, there has been comparatively little exploration of their experiences therein, especially within the context of cancer care. Drawing on semi-structured qualitative interviews with 16 Australian male carers for a relative with cancer … the authors explore their experiences of informal caring. Their analysis highlights a series of tensions: the meanings and practicalities of care provision including notions of reciprocity, duty, autonomy, and interdependence; the discomforts of dependency and vulnerability; and, the complicated moralities that inflect "caring well." Given the shifting dynamics around informal care, the authors argue for increased attention to the affective tensions that arise at the nexus of moralities and masculinities in informal caring relations, especially as they are articulated in the context of illness, affliction, and dependency. **Abstract:** http://bit.ly/2XpCTEY

Disentangling public preferences for health gains at end-of-life: Further evidence of no support of an end-of-life premium

SOCIAL SCIENCE & MEDICINE | Online – 21 June 2019 – In many countries, it has been publicly debated whether health gains for patients at end-of-life (EoL) should be valued higher than health gains for other patients. This has led to a range of stated preference studies examining the justification for an EoL premium on the basis of public preferences – so far with mixed findings. A web-based survey was conducted in 2015 using a random sample of 1,047 members of the general public in Denmark. Overall, the authors did not find evidence to support an EoL premium compared to other health gains, neither when preferences are elicited from a social nor an individual perspective. Furthermore, their results demonstrate that the type of the health gain received matters to preferences for treatment at EoL with more weight given to gains in quality of life than gains in life expectancy. Finally, the authors found heterogeneity in preferences according to respondent characteristics, perspectives and age of beneficiaries. **Abstract:** http://bit.ly/2IuSHhb

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF CRIMINAL LAW & CRIMINOLOGY*, 2019;109(3). '**Death with dignity for the seemingly undignified: Denial of aid in dying in prison.**' The conversation surrounding quality of life, and by extension end-of-life care, has included whether a competent adult has a right, or should have a right to end their own life on their own terms. The history of aid in dying is wrought with political ideology, notions of morality, and discussions of autonomy. In the wake of an aging population, aid in dying is more relevant now than ever. Aid in dying is often supported by notions of autonomy and dignity in choosing the conditions of if, when, and how to end one's life, however, there is one noticeable segment of the population entirely left out: incarcerated individuals. The incarcerated population is particularly relevant to the aid in dying conversation because, as the justice system continues to balloon and incarcerate more people, prisons are overcrowded, underfunded, and ill-equipped to support terminally ill and aging inmates. This leaves the aging incarcerated population vulnerable. As states [in the U.S.] continue to contemplate and pass legislation that permits aid in dying in particular circumstances, one is left wondering how, if at all, this legislation will affect those incarcerated. Early signs, in the form of prison policies and regulations, of how prisons will approach aid in dying for qualifying inmates suggests that the same dignitary respect afforded to non-incarcerated folk is explicitly forbidden to inmates in prison. **Download/view full text at:** http://bit.ly/2MUD0nI

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., (updated 20 May 2019) noted in past issues of the weekly report can be downloaded/viewed on the Palliative Care Network website at: http://bit.ly/2RdegnL

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.

Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

Links to Sources

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Updated 06.20.2019

Media Watch: Access on Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://bit.ly/2Xo5pqe

[Scroll down to 'Media Watch']

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

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

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

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

Asia

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

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

Canada

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

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

Cont.

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): http://bit.ly/2TboKFX

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): HTTP://BIT.LY/2RQGTUX

HUNGARY | Magyar Hospice Alapítvány: http://bit.ly/2RgTvYr

U.K. | Omega, the National Association for End-of-Life Care: http://bit.ly/2MxVir1

South America

Academia Nacional de Cuidados Paliativos (Brazil): http://bit.ly/2G2ISGr

Barry R. Ashpole, Ontario CANADA **e-mail: barryashpole@bell.net**