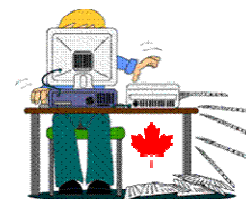


Media Watch...

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

There are inherent limitations in how current evidence-based palliative care accounts for the increasingly “messy world of practice.”

‘Evidence-based palliative care: How can we account for the messy world of practice?’ (p.11), in *Palliative Medicine*.

Canada

Campbellton palliative patients moved into different unit because of nurse shortage

NEW BRUNSWICK | CBC News (Fredericton) – 12 July 2019 – Palliative care (PC) patients are being moved out of their separate unit into another unit of the Campbellton Regional Hospital because of a shortage of nursing staff. The six PC beds are being moved to the geriatric-rehabilitation unit ... said Gilles Lanteigne, president and CEO of the Vitalité Health Network. The changes will be in effect until October, when the health authority will re-evaluate the situation. The PC unit closed down earlier this year because of a staffing shortage resulting from illnesses and workers on leave of absence. New Brunswick's minister of post-secondary

education, training and labour has promised a 10-year strategy to deal with the province's nursing shortage will be announced in the next few weeks. <http://bit.ly/2NPoloR>

Specialist Publications

‘Shades of gray: Conscientious objection in medical assistance in dying’ (p.14), in *Nursing Inquiry*.

‘A qualitative study of physicians’ conscientious objections to medical aid in dying’ (p.14), in *Palliative Medicine*.

Noted in Media Watch 23 April 2018 (#560, p.1)

- NEW BRUNSWICK | Global TV News (Fredericton) – 19 April 2018 – ‘**New Brunswick announces palliative care strategy framework.**’ The Government of New Brunswick announced its framework for a palliative care (PC) strategy to help improve access to palliative and end-of-life care services.¹ New Brunswick Seniors & Long-Term Care Minister Lisa Harris said an advisory committee will be set up to develop an action plan. The committee will be led by the New Brunswick Cancer Network, made up of representatives from PC, health care, and community stakeholders. <http://bit.ly/2XFpjhq>

1. ‘Palliative Care in New Brunswick: A person-centred care and integrated services framework,’ Department of Health, Government of New Brunswick, April 2018. **Download/view at:** <http://bit.ly/2EUoQwY>

U.S.A.

Hospice, palliative care education bill introduced in Senate

HOSPICE NEWS | Online – 12 July 2019 – The Palliative Care & Hospice Education & Training Act has been introduced in the U.S. Senate. The legislation would provide resources to support clinician training to reduce staff shortages in the industry and help providers meet continuously rising demand for those services as the population ages. If enacted, the bill would establish fellowship programs within new palliative care (PC) and hospice education centers to provide short-term, intensive training on PC and hospice. The courses would provide supplemental training for medical school faculty as well as other educators in health care fields such as nursing, pharmacy, social work and chaplaincy. The centers would also develop curricula related to PC and support continuing education, retraining of faculty, practical clinical training and establish training programs for advanced practice nurses. A version of the bill was introduced in the U.S. House of Representatives in April. The House Committee on Energy & Commerce is currently reviewing the House bill. <http://bit.ly/32mKow5>

Health & Human Services Inspector General finds serious flaws in 20% of U.S. hospice programs

NATIONAL PUBLIC RADIO | Online – 9 July 2019 – We all hope for some peace and comfort at the end of life. Hospices are designed to make that possible, relieving pain and providing emotional and spiritual support. But two new government studies¹ ... find that the vast majority of hospices have sometimes failed to do that. And there's no easy way for consumers to distinguish the good hospices from the bad. The reports are the government's first to look at hospice deficiencies nationwide. The Office of the Inspector General in the Department of Health & Human Services found that through from 2012 2016, health inspectors cited 87% of hospices for deficiencies. And 20% of hospices had lapses serious enough to endanger patients. <https://n.pr/2xND1zL>

Characteristics of poor performers

- 88 percent had a history of other violations
- 67 percent were for-profit, similar to hospices nation-wide
- 40 hospices had a history of serious deficiencies

1. 'Hospice Deficiencies Pose Risk for Medicare Beneficiaries,' Office of the Inspector General, Department of Health & Human Services, July 2019. **Download/view at:** <http://bit.ly/2XTBPJH>

Noted in Media Watch 6 August 2018 (#575, p.3):

- WASHINGTON DC | *Kaiser Health News* – 31 July 2018 – '**Missed visits, uncontrolled pain and fraud: Report says hospice lacks oversight.**' A report from the Office of Inspector General at the Department of Health & Human Services sums up over 10 years of research into inadequate care, inappropriate billing and outright fraud by hospices, which took in \$16.7 billion in Medicare payments in 2016.¹ An investigation in 2017 revealed that while many of the nation's 4,000-plus hospices earn high satisfaction rates on family surveys, hundreds fell short of their obligations, abandoning families at the brink of death or skipping other services they had pledged to provide.² <http://bit.ly/2JrMHpV>
 1. 'Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity: An OIG Portfolio,' Office of Inspector General, U.S. Department of Health & Human Services, July 2018. **Download/view at:** <http://bit.ly/2YKJreH>
 2. "'No one is coming": Investigation reveals hospices abandon patients at death's door,' *Kaiser Health News*, published online 26 October 2017. [Noted in 30 October 2017 issue of Media Watch (#536, pp.4-5).] <http://bit.ly/2LOaou7>

What happens to medically fragile children when they age out of pediatric care? Often, they die

NEW YORK STATE | *Rockland/Westchester Journal News* (White Plains) – 8 July 2019 – Medical advances mean more children with complex health challenges live to adulthood. But that's led to a tragic statistic: 30% of children who age out of Elizabeth Seton Children's Center on their 22nd birthday die within 14 months... That's why Seton has reached out to the New York State Department of Health to create a new kind of facility for young adults, ages 22 to 35. Elizabeth Seton Children's Center currently cares for 169 children, making it the largest pediatric nursing home facility in the nation. With some 3 million children with critical medical conditions living in the U.S., more families and facilities will face the same stark choices about post-pediatric care. Current options include sending patients to group homes, geriatric nursing homes or back to their families' care. Each pose inherent risks. Group homes aren't often able to treat patients' medical needs. Geriatric nursing homes often lack the kind of social stimulation and intense care young patients need. And children aren't being cared at home for a reason – because they need constant, professional support. <http://bit.ly/2XAqwXj>

Noted in Media Watch 5 November 2018 (#588, p.13):

- *PEDIATRICS*, 2018;142(5):e20182587. **'Supporting the healthcare transition from adolescence to adulthood in the medical home.'** This report provides practice-based quality improvement guidance on key elements of transition planning, transfer and integration into adult care for all youth and young adults. It includes sections on definition and guiding principles, the status of healthcare transition preparation among youth, barriers, outcome evidence, recommended healthcare transition processes and implementation strategies using quality improvement methods, special populations, education and training in pediatric onset conditions, and payment options. **Full text:** <http://bit.ly/2F99J2n>

Of related interest:

- 'Evaluation of a pilot service to help young people with life-limiting conditions transition from children's palliative care services,' *International Journal of Palliative Nursing*, 2018;24(7):322-332. **Abstract:** <http://bit.ly/2ZtsNAh>
- 'Conflicting realities experienced by children with life-limiting and life-threatening conditions when transitioning to adult health services,' *Journal of Advance Nursing*, 2018;74(12):2871-2881. **Abstract:** <http://bit.ly/2IFXs6v>

POLST: Promise and pitfalls in skilled nursing centers

PROVIDER | Online – 8 July 2019 – The acronym POLST historically has denoted Physician Orders for Life-Sustaining Treatment, but the National POLST Paradigm is now moving away from the original meaning and just retaining the word POLST because it is familiar to many people. The reasons include emphasizing that not just physicians are involved but that the entire POLST process, from goals of care conver-



Current thinking in paediatric palliative care and transition to adult care

A selection of articles that focus on the "current thinking" in paediatric palliative care, including a selection of articles specific to end-of-life care for adolescents and their transition to adult care, posted 8 July 2019 on the European Association for Palliative Care blog at: <http://bit.ly/2XC24jA>

[Specialist Publications](#)

'The conceptual understanding of pediatric palliative care: A Swiss healthcare perspective' (p.8), in *BMC Palliative Care*.

National
POLST
Paradigm

Cont.

sation to completion of the form, is a team process; that other licensed healthcare professionals are able to sign the form; and that the term “life-sustaining treatment” is somewhat value-laden: It seems to imply that placing a feeding tube in a person with advanced dementia or doing cardiopulmonary resuscitation on a 75-pound nonagenarian with advanced cancer would in fact be “life-sustaining.” It’s important to note that POLST orders are meant to reflect the end result of diligent, careful, detailed conversations between the healthcare team and the patient (and/or surrogates). A POLST form should never be just a check-box form that is part of a pile of admission documents, and it should not be completed in a cursory manner. This is a life-and-death document, and it needs to be treated that way. **Full text:** <http://bit.ly/32kMUD5>

N.B. Additional articles on POLST noted in 27 May 2019 issue of Media Watch (#615, p.7) reporting on, for example, national standards and state variations in POLST, how well POLST forms assure that patients get the end-of-life care they requested, and lessons learned from state-based developments. National POLST Paradigm website: <http://bit.ly/2xAEQjC>

First compassionate care program in state offers inmates chance to care

VIRGINIA | *The Daily Progress* (Charlottesville) – 7 July 2019 – In April, Melanie Mason, a social worker for the Hospice of the Piedmont, received a call from the Fluvanna prison, notifying her that a new inmate had previously received hospice care at a different facility and had requested hospice care at Fluvanna. The Hospice of the Piedmont provides end-of-life care and services to people within a geographic region, services that are often reimbursed by Medicare, Medicaid and insurance plans. Mason’s coverage area includes Fluvanna County, so she began coordinating care efforts. The prison didn’t have trained medical staff who were available to sit by the woman’s bed 24/7, so Mason, hospice nurse Ruth Hurley and prison nurse manager Mikayla Osborne suggested asking other inmates to volunteer. “This was a patient who didn’t have a

strong family background and unfortunately had to do this process [of dying] by herself,” Osborne said... “When Melanie brought up giving compassionate care to the patient, it was an epiphany, and we rolled with it.” With Aldridge’s approval, they asked the prison’s honor wing – a set of women who have a history of good behavior – if they wanted to participate, and inmates started “coming out of the woodwork,” Mason said. <http://bit.ly/2JGvNTJ>

Specialist Publications

‘Developing computer-based learning on care of aged and dying incarcerated people’ (p.10), in *Journal of Forensic Nursing*.

Noted in Media Watch 8 April 2019 (#609, p.10):

- *JOURNAL OF WOMEN & AGING* | Online – 4 April 2019 – ‘**Healthcare needs of older women prisoners: Perspectives of the healthcare workers who care for them.**’ This study sought to elucidate the unique healthcare needs of older women prisoners through the perspectives of correctional healthcare providers. Three organizing themes emerged regarding the health of older women prisoners: 1) The meaning of being “older” in the prison setting; 2) Challenges impacting correctional healthcare workers’ care delivery; and, 3) Unmet healthcare-related needs. Correctional healthcare workers’ insights can provide guidance regarding how to optimize the health of the increasing population of older women prisoners. **Abstract:** <http://bit.ly/2uNwbsf>

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., 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 Online

Updated 07.08.2019

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.15

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CALIFORNIA | Capital Public Radio (Sacramento) – 12 July 2019 – **‘California’s Aid In Dying Law is mostly used by white people. Here’s why.’** Roughly 88% of people using California’s physician-assisted death law are white, according to new data from the California Department of Public Health (CDPH). That’s been the case every year since the law took effect in 2016. Jill Weinberg, a sociologist at Tufts University, has been tracking the roll-out of aid-in-dying laws across the U.S. She notes that many of the states that have passed these policies so far, such as Oregon, Washington, and Vermont, are primarily white. “California is the first state in which we’re starting to expect to see more diversity,” she said. “And in fact, we’re not seeing that.” Last year 452 people received a prescription and 337 people died from ingesting drugs acquired through the law, according to the CDPH data. Experts say the racial breakdown of who’s using the option reflects a larger problem of who’s accessing treatment for terminal illness. <http://bit.ly/2NQgwF1>

[Specialist Publications](#)

‘Hospital and health system policies concerning the California End of Life Option Act’ (p.14), in *Journal of Palliative Medicine*.

[International](#)

Institute of Policy Studies report wants Singapore families, society to discuss and better plan end-of-life matters

SINGAPORE | *The Straits Times* – 12 July 2019 – When it comes to talking about death and dying, Singaporeans uncharacteristically leave things to the last minute. But this has to change as the country ages, with a robust national plan needed to prepare people for their final days, recommends the Institute of Policy Studies (IPS) in a comprehensive new report...¹ “As Singaporeans, we plan for almost everything, from the first house that we purchase to the child’s first school,” said IPS research associate Yvonne Arivalagan, one of the study’s authors. “But this is a really important aspect of life that very few people actually plan for.” The 97-page report highlighted aspects of end-of-life care where gaps remain and recommended improvements, including in the areas of costs, family support, and the ease of planning out and communicating one’s final wishes. It is based on the findings of a group of experts from various fields, who studied the issue over a two-year period. “We find that one of the most common scenarios is that people just don’t talk about this until it’s too late,” Ms Arivalagan added. <http://bit.ly/2JCDxWL>

[Specialist Publications](#)

‘Managing end-of-life care in Malaysia: The economic considerations from the ethical and Islamic perspective’ (p.7), in *Al-Shajarah: Journal of the International Institute of Islamic Thought & Civilization*.

‘Comparison of financial support for family caregivers of people at the end of life across six countries: A descriptive study’ (p.11), in *Palliative Medicine*.

‘Palliative care for older South Asian migrants: A systematic review’ (p.12), in *Palliative & Supportive Care*.

‘Palliative care ethical guidelines to assist health-care practitioners in their treatment of palliative care patients’ (p.13), in *South African Journal of Bioethics & Law*.

1. ‘Leaving Well: End-of-Life Policies in Singapore,’ Institute of Policy Studies, July 2019. **Download/view at:** <https://nus.edu/2JwWStu>

53,900 opt out of life-prolonging treatment since adoption of Death with Dignity Act

KOREA | *The Korea Herald* (Seoul) – 11 July 2019 – The number of individuals who either withheld or withdrew from receiving life-prolonging treatment totaled 53,900 as of 30 June. The end-of-life care legislation allowing terminally ill patients to abandon life-prolonging medical care went into effect on 4 February 2018. Life-prolonging treatment refers to medical procedures that delay the process of dying with no significant chance of resulting in recovery from or alleviation of suffering. In addition to four treatments categorized as life-prolonging measures – CPR, artificial ventilation, hemodialysis and chemotherapy – the Ministry of Health & Welfare expanded the scope in March to include procedures such as extracorporeal life support, transfusion and vasopressor therapy. Terminally ill patients can withhold or withdraw consent for receiving life-prolonging treatment through a written statement. In cases where the patient lacks capacity to make a decision, two or more family members can testify the patient would not wish to prolong treatment on his or her behalf. <http://bit.ly/2JBX61o>

Benefits system for terminally ill people to be reviewed

U.K. (England, Northern Ireland & Wales) | *The Guardian* (London) – 11 July 2019 – The work and pensions secretary has announced a review of the benefits system for terminally ill claimants... Citing her own experiences, Rudd suggested there should be reform of the current process for those nearing the ends of their lives, whose benefits are subject to special rules for terminal illness, which have come under heavy criticism from charities. The rules mean that if a person is living with a terminal illness they can have their benefit claim fast-tracked and paid at an enhanced rate, but many charities ... have campaigned for claimants not to have to prove that they have six months or less to live. The system has been heavily criticised by charities for denying benefits in some cases to people who have died shortly afterwards and asking insensitive questions such as to name a date when they expect to die. Announcing the review, Rudd's department said the rules were often seen as favouring those living with cancer when other illnesses can also limit life. The review will involve three strands of research, including hearing from claimants and charities about their experiences, consideration of international evidence, and an analysis of current performance. About 500,000 people die in England each year,

and there are now many more people who are living with severe or progressive health conditions. <http://bit.ly/2SbnnXX>



National Audit of Care at the End of Life

U.K. (England & Wales) | Healthcare Quality Improvement Partnership (London) – Accessed 12 July 2019 – The 'National Audit of Care at the End of Life' is a comparative audit of the quality and outcomes of care in England & Wales experienced by the dying person and those important to them during the last admission leading to death. It looks at care in acute, community hospitals and mental health inpatient providers. Around a quarter of a million people die in hospital each year in England & Wales and the audit results suggest 75% of bereaved people feel that this was the right place for the person important to them to die. This audit reviews how people's preferences regarding care at the end of life are identified, discussed and implemented during their last admission in acute and community hospitals. **Download/view at:** <http://bit.ly/2LhXa9J>

Noted in Media Watch 8 July 2019 (#621, p.2):

- U.K. (England, Northern Ireland & Wales) | *The Independent* (London) – 3 July 2019 – **'Terminally ill "denied lifeline" as they are forced to go through "burdensome" benefits process, finds report.'** Terminally ill people are being denied the "lifeline they need" because they are forced them to go through a "burdensome" process to access benefits, MP's have warned. The government's definition of terminal illness states that a person's death can be reasonably expected within six months. But this was described as "outdated, arbitrary and not based on clinical reality" by the All-Party Parliamentary Group for Terminal Illness.¹ <http://bit.ly/2XHjkrL>

1. 'Six Months To Live? Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness,' July 2019. **Download/view at:** <http://bit.ly/2XJTXp8>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- LUXEMBOURG | *Delano Magazine* – 11 July 2019 – ‘**Euthanasia to be equated with death by natural causes.**’ Ten years after the coming into force the law on euthanasia and assisted suicide will now include legislation that defines the death of a person who has died as a result of euthanasia or assisted suicide with death by natural causes. Health minister Étienne Schneider ... said that the new bill will “clarify the consequences” of deaths by assisted suicide or euthanasia “particularly with regard to the circumstances of death, and the context of any life insurance that the deceased may have taken out.” Since the law entered into force some 72 people have died by euthanasia, with no more than 11 deaths (in 2017) in any given year. The law requires that the patient be in a hopeless medical situation and report constant and unbearable physical or psychological suffering resulting from an accidental or pathological condition. Medical testimony must state that they have no prospect of improvement before they can be considered for euthanasia. <http://bit.ly/32l3jau>

Specialist Publications

Managing end-of-life care in Malaysia: The economic considerations from the ethical and Islamic perspective

AL-SHAJARAH: JOURNAL OF THE INTERNATIONAL INSTITUTE OF ISLAMIC THOUGHT & CIVILIZATION, 2019;24(1):131-157. Since the turn of the 20th century, the increase in the degree of medical prevalence particularly at the end of life (EoL), has redefined the dimensions between life and death. Medical treatment and equipment are now able to prolong the life expectancy of patients suffering from life-limiting illnesses even in the absence of any brain activity. This has impacted upon the delivery of EoL care, which focuses on providing a comfortable environment for patients who are suffering from incurable diseases and for whom death is imminent. The emergence of sophisticated medical devices and interventions has raised ethical issues relating to EoL decisions especially in

withholding or withdrawing life sustaining treatments. In such a situation, economic considerations constitute an important factor in the provision of EoL care due to the costly and limited resources which are required for providing such life-sustaining treatment. Healthcare providers need to grapple with issues justifying resource allocation amongst patients, which are in turn contingent upon deliberations on medical futility.

Abstract: <http://bit.ly/2NGXW24>

Publishing Matters

‘Why India is striking back against predatory journals’ (p.14), in *Nature*.

N.B. Additional articles on the Islamic perspective on EoL and EoL care noted in 17 June 2019 (#618, p.10).



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>

The conceptual understanding of pediatric palliative care: A Swiss healthcare perspective

BMC PALLIATIVE CARE | Online – 11 July 2019 – Despite important changes in the formal definition of pediatric palliative care (PPC), it has still a overly negative connotation in the minds of many parents and healthcare providers. To counter this trend, calls have been made to initiate PPC at diagnosis and if necessary, rebrand the term PPC as supportive or comfort care. Many participants in this study seemed critical about the “from diagnosis onward” directive and clearly associated PPC with non-curative treatment. To most of them, the adequate timing of PPC remained a major challenge. Although the philosophical definition of PPC leaves room for patient individuality, it complicates clinical practice as it does not provide clear protocols. More referral tools are needed to help oncologists to identify children and families with palliative care needs. Further, although PPC has increasingly profiled itself as being concerned with the patient’s quality of life (rather than with death) this shift has not overcome all stigmas. Therefore, perhaps the conceptual obstacle to PPC is not so much death itself, but the way in which PC is discussed on both a policy level and in public debates, that is, in terms of choice, autonomy and personal development. This interpretation could find support in the fact that our participants considered the term “palliative care” to be out of touch with the child’s perspective and preferred to use synonyms that are closer to PC’s original aims: to offer support to patients and families in pain, anger, sadness and laughter without any normative expectations. **Full text:** <http://bit.ly/2XGKTSH>

Related

- *ACTA PAEDIATRICA* | Online – 12 July 2019 – ‘**Telling the truth to dying children: End-of-life communication with families.**’ Communicating a terminal prognosis is challenging for patients, families and healthcare professionals. However, positive effects have been reported when children are told about their diagnosis and prognosis, including fewer symptoms of anxiety and depression and enhanced adherence to treatment. When research about prognostic communication was first published in the 1950s and 1960s, it recommended protecting children from bad news. By the late 1960s, a more open approach was recommended and by the late 1980s the advice was to always tell children. There has been a growing awareness of the complexity of prognostic disclosure and the need to balance often competing factors, such as hope and patient and family considerations, on a case-to-case basis. **Abstract:** <http://bit.ly/2LQ1We4>

How do hospital-based nurses and physicians identify the palliative phase in their patients and what difficulties exist? A qualitative interview study

BMC PALLIATIVE CARE | Online – 9 July 2019 – Nurses and physicians [i.e., study participants] feel insecure about how to define the palliative phase and differentiate between an acute and extended phase. Great variation existed in what life expectancy is attributed to each phase. A variety of ways to identify the palliative phase were described: 1) Prognostication; 2) Treatment trade-off; 3) Assessment of patients’ preferences and needs; and, 4) Interprofessional collaboration. Professionals base prognostication on their experience but also search for clinical indicators. When benefits of treatment no longer outweigh the negatives, this was considered an, albeit late, identification point. To start a conversation on a patients’ palliative care needs was found to be difficult. Therefore, some respondents wait for patients to vocalize preferences themselves. Many professionals rely on interprofessional collaboration for identification, however uncertainty exist about responsibilities. **Full text:** <http://bit.ly/2XDI0C6>

Related

- *BMJ OPEN* | Online – 9 July 2019 – ‘**The (un)availability of prognostic information in the last days of life: A prospective observational study.**’ The most prevalent prognostic features observed were a decrease in oral food intake (60%) and a rapid decline of the participant’s global health status (56%). Participants who died within 72 hours had a lower level of consciousness and had more care needs than those who lived longer. A large portion of data was unavailable, particularly that relating to the psychological and spiritual well-being of the patient, due to the decreased consciousness of the patient. The prevalence of prognostic signs and symptoms in the final days of life has been documented between those predicted to die and those who did not. How doctors make decisions with missing information is an area for future research, in addition to understanding the best way to use the available information to make more accurate predictions. **Full text:** <http://bit.ly/2JBZwNI>

Palliative care for persons with Parkinson's disease: A qualitative study on the experiences of healthcare professionals

BMC PALLIATIVE CARE | Online – 9 July 2019 – Healthcare professionals [i.e., study participants] supported the development of a palliative care (PC) system for Parkinson's disease (PD), but needed to better understand the essence of PC. In daily practice, they struggled to identify persons' needs due to interfering PD-specific symptoms such as cognitive decline and communication deficits. Timely addressing the personal preferences for providing PC was identified as an important facilitator. Healthcare professionals acknowledged being aware of their lack of knowledge and of their little competence in managing complex PD. Findings indicate a perceived lack of care continuity, fragmentation of services, time pressure and information discontinuity. **Full text:** <http://bit.ly/2xDD29a>

Noted in Media Watch 17 September 2018 (#581, p.13):

- *JOURNAL OF PARKINSON'S DISEASE* | Online – 20 August 2018 – **'Parkinson matters.'** A report by Public Health England provides insight on trends in deaths associated with neurological diseases in England between 2001 to 2014.¹ Data suggest the end-of-life for Parkinson's disease (PD) patients is often unplanned, occurring in hospitals or care homes. Although there are undeniably instances when dying in a hospital is more appropriate than dying at home, most patients indicate a preference for dying at home. The vast majority of hospital admissions of PD patients are unplanned, resulting from either complications of the disease or its treatments or comorbidities. **Full text:** <http://bit.ly/2NNGbhu>

1. 'Deaths associated with neurological conditions,' Public Health England, February 2018. **Download/view at:** <http://bit.ly/2XEYJ3g>

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 September 2018 – **'Top ten tips palliative care clinicians should know about Parkinson's disease and related disorders.'** Parkinson's disease (PD) affects 1-2% of individuals older than 60 years and is the 14th leading cause of death in the U.S. People with PD, across all stages of the disease, suffer from a significant symptom burden that includes many non-motor symptoms and most will ultimately die from complications of this degenerative and incurable illness. Even at diagnosis, a palliative care approach can help the patient adjust to his or her diagnosis and maintain an optimal quality of life. **Abstract:** <http://bit.ly/2YTAYpL>

N.B. Additional articles on the end-of-life care for patients living with PD noted in 20 August 2018 issue of Media Watch (#577, p.9).

End-of-life care for people with alcohol and drug problems: Findings from a Rapid Evidence Assessment

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 11 July 2019 – This Rapid Evidence Assessment set out to explore current responses to and models of practice for, people living with problematic substance use and palliative and end-of-life care (EoLC) conditions. There is a dearth of research available on this topic and thus the focus of this review was broadened to identify what evidence was available, its focus, quality and the gaps in the research evidence base. The resulting body of work comprised 60 papers, primarily from peer-reviewed journals. It was quite disparate in focus, with a diverse range of research populations, research questions and methodological choices. The available evidence resulted in two clear, but limited, groups of papers, those focussing on pain management and prescribing and those focussing on homelessness, substance use and EoLC. A third group included a small body of work on alcohol and palliative or EoLC and a small number of other papers including co-existing mental health or HIV-related conditions. This is clearly an area of work where far more research is needed. It is a new area of work and research focus and that has to be considered in considering the authors' findings. However, the gaps identified are considerable and need to be filled in order to provide an evidence base on which to build future good policy and practice, both in the U.K. and internationally. Ultimately, this work is needed to ensure that this growing group of people have good quality care and equal access to service provision. **Full text:** <http://bit.ly/2JxJbul>

Cont.

Noted in Media Watch 20 May 2019 (#614, p.4):

- U.K. (England) | *About Manchester* – 16 May 2019 – ‘**Adopt new policy standards for terminally ill patients with substance use problems, says report.**’ Researchers have outlined six policy standards urging policy-makers, National Health Service commissioners and service providers to introduce measures that would improve provision and tackle stigma towards terminally ill patients who are, or have been, problematic users of alcohol or other drugs.¹ The recommendations – the first of their kind in the U.K. – are based on consultation with professionals in leadership and policy roles across health and social care services in Liverpool, particularly specialist palliative, end-of-life and substance use services. <http://bit.ly/2W65Hle>

1. ‘Policy Standards: A Working Document. Palliative and End-of-Life Care for People with Alcohol and Drug Problems,’ (1st edition), Manchester Metropolitan University, May 2019. **Download/view at:** <http://bit.ly/2w0StY3>

N.B. Additional articles on terminal ill patients with drug and alcohol addictions noted in 19 November 2018 issue of Media Watch (#590, pp.13-14).

Developing computer-based learning on care of aged and dying incarcerated people

JOURNAL OF FORENSIC NURSING | Online – 9 July 2019 – The authors describe the design and development of a media-rich interactive computer-based learning product, which addresses geriatric and end-of-life care issues in corrections. The Enhancing Care for Aged & Dying in Prison contains six modules, created under the careful guidance of the research team and the two advisory boards. Contents, including images and testimonials, were selected purposefully and strategically. Module objectives were developed in alignment with the goals and priorities of each module, and assessments tested user knowledge level pre/post module exposure. Evidence-based training products are critical in preparing not only forensic nurses who work in corrections but also the broader group of correctional personnel in how to better meet the care needs of incarcerated persons. **Abstract:** <http://bit.ly/2XWGtqn>

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., noted in past issues of the weekly report, can be downloaded/viewed on the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Navigating the path to care and death at home – it is not always smooth: A qualitative examination of the experiences of bereaved family caregivers in palliative care

JOURNAL OF PSYCHOSOCIAL ONCOLOGY RESEARCH & PRACTICE, 2019;1(1):e3. Support provided by professional palliative care (PC) services and community care workers through the Supportive Palliative Care Packages was valued by family caregivers (FCGs) for enabling choice, if it was their preference to realize end-of-life care in the home, and provided practical assistance, emotional support, and reassurance. Death may be natural but best practice PC requires skilled assessment and care, even for an “uncomplicated” death. Understanding the complexities of end-of-life care and the support needs of FCGs in the home setting could improve services. Relationships where families and patients are partnered with, mentored, empowered, and feel comfortable with clinicians and volunteer caregivers are valued. Flexible practical assistance is valued highly and care arrangements that are not flexible may be more harmful than helpful for some families. Models of care that are based on the assumption that home death is straightforwardly beneficial may cause unintended consequences. Thus, providing care in the private space of the home requires close attention to family concerns, resources and outcomes. A deeper understanding of the costs and benefits of families’ caregiving in the context of PC bereavement will contribute to the development of models of community palliative care. **Full text:** <http://bit.ly/2xJ6YRg>

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- *EVIDENCE-BASED NURSING* | Online – 10 July 2019 – ‘Access to specialist palliative care to manage pain in people dying at home: Give them a VOICE.’ People who receive specialist palliative care or have a stated preference to die at home have a significantly higher chance of experiencing good pain relief as they die, irrespective of their disease aetiology. **Summary:** <http://bit.ly/2JLEX0W>

N.B. The authors of the *Evidenced-Based Nursing* article comment on ‘Specialist palliative care support is associated with improved pain relief at home during the last 3 months of life in patients with advanced disease: Analysis of 5-year data from the national survey of bereaved people (VOICES),’ *BMC Medicine*, published online 22 March 2019. [Noted in Media Watch 25 March 2019 (#607, p.8)] **Full text:** <http://bit.ly/2HBMoZV>

The performance of researching sensitive issues

MORTALITY | Online – 10 July 2019 – Within sociological and organisational literature much attention has been paid to the emotional labour and emotion work performed by care staff. By contrast, comparatively little attention has been paid to that which researchers perform and how it is shaped by the need to behave appropriately and in ways that are in keeping with the demands of the study setting. Existing literature focuses largely on the need for researchers to be aware of their emotions as part of being reflexive and thus, through acknowledgement, minimising any emotional impact (subjectivity) on research interpretations. The authors draw on two research experiences, an ethnographic study into end-of-life care in care homes and an exploration into the role of the anatomical pathology technologist in a hospital mortuary to explore the tensions between conducting sensitive research and managing emotions. **Abstract:** <http://bit.ly/2Y6ydnS>

Comparison of financial support for family caregivers of people at the end of life across six countries: A descriptive study

PALLIATIVE MEDICINE | Online – 12 July 2019 – Family caregivers (FCGs) of people at the end of life (EoL) can face significant financial burden. While appropriate financial support can reduce the burden for family caregivers, little is known about the range and adequacy of financial support, welfare and benefits for FCGs across countries with similarly developed healthcare systems. A survey of financial support, welfare and benefits for EoL FCGs was completed by 99 palliative care experts from the six countries. Grey literature searches and academic database searches were also conducted. Comparative analyses of all data sources documented financial support within and between each country. Some form of financial support for FCGs is available in all six countries; however the type, extent and reach of support vary. Financial support is administered by multiple agencies, eligibility criteria for receiving support are numerous and complex, and there is considerable inequity in the provision of support. Numerous barriers exist to the receipt of financial support, welfare and benefits. The authors identified several areas of concern, including a lack of clarity around eligibility, inconsistent implementation, complexity in process and limited support for working carers. Nonetheless, there is significant potential for policymakers to learn from other countries’ experiences, particularly with regard to the scope and operationalisation of financial support. **Abstract:** <http://bit.ly/2XEwmqJ>

Evidence-based palliative care: How can we account for the messy world of practice?

PALLIATIVE MEDICINE | Online – 9 July 2019 – There are inherent limitations in how current evidence-based palliative care (PC) accounts for the increasingly “messy world of practice.” For example, the persistent use of anticholinergic drugs for respiratory tract secretions, despite a lack of research evidence to support their use, underscores how difficult it can be to apply clinical research in PC. Evidence in PC reflects a complex constellation of “constructed facts, propositions, experiences, biographies and histories and is ultimately an exercise of judgement bounded by time and context.” We need to better understand how healthcare professionals of any discipline and in all care settings and PC populations balance research findings, guidelines, protocols and policies with clinical judgement and individualising care *in situ*. **Full text:** <http://bit.ly/2JuVMP4>

Cont.

Noted in Media Watch 27 May 2019 (#615, p.14):

- *MÉDECINE PALLIATIVE* | Online – 22 May 2019 – ‘**Redesigning the evidence synthesis in palliative care: The realist review.**’ Evidence-based medicine is an ideal that challenges palliative care (PC) practice, especially because the knowledge synthesis is highly difficult in this field. Despite the fact that systematic reviews offer a rigorous synthesis of the evidence, they face limits of their evaluative objectives. They do not offer an overall understanding of why and how a complex intervention is efficient in a specific context. Initially developed in social sciences, the realist review might be a more accurate solution to address issues specific to PC. **Abstract:** <http://bit.ly/2HXaOe9>

N.B. French language article.

Noted in Media Watch 23 November 2015 (#437, p.15):

- *CANCER BIOLOGY & MEDICINE*, 2015;12(3):193-200. ‘**Reality of evidence-based practice in palliative care.**’ It remains true in 2015 that despite the growth in published literature, palliative care is not an evidence-based discipline, or at least it is not informed by the level of evidence which most would require to label it such. This is for entirely predictable and understandable reasons. The patient population, the unique aims of treatment and the trajectory of incurable disease all conspire to make the traditional “gold-standard” of randomised controlled trials a challenging and, at times, inappropriate model with which to drive improvements in care. **Full text:** <http://bit.ly/2NLWQlv>

Validation of a palliative care outcome measurement tool supplemented by neurological symptoms (HOPE+): Identification of palliative concerns of neurological patients

PALLIATIVE MEDICINE | Online – 8 July 2019 – There is growing interest to integrate palliative care (PC) and its structures into the care of neurological patients. However, in Germany there is no comprehensive assessment tool capturing the symptoms of patients with advanced neurological diseases. Hospice & Palliative Care Evaluation considering additional neurological issues (HOPE+) demonstrates promising psychometric properties. It helps to assess PC issues of patients in neurological settings and, in combination with the 12-months “surprise” question, conceivably conditions when to initiate the PC approach in a population underrepresented in PC structures so far. **Abstract:** <http://bit.ly/2Jgelyh>

N.B. Additional articles on PC for patients living with motor neurone disease noted in 6 May 2019 issue of Media Watch (pp.5-6).

Palliative care for older South Asian migrants: A systematic review

PALLIATIVE & SUPPORTIVE CARE | Online – 8 July 2019 – South Asian migrants have a higher burden of life-threatening diseases and chronic diseases compared to other ethnic groups. Yet, knowledge gaps remain around their palliative care (PC) needs in the host countries. The aim of the review was to present results from a systematic literature review of available international evidence on experiences with and perspectives on PC among older South Asian migrants, relatives, and healthcare providers. Thirty articles were included: qualitative (24), quantitative (5), and mixed methods (1). Three main themes were discovered: 1) PC practice within the family; 2) Trust as a precondition of PC; and, 3) The importance of knowledge and cultural competency. All the themes, to a greater or lesser extent, are related to access to and use of PC services by South Asian migrant families. Involvement of family members in PC decision making could improve the satisfaction of South Asian migrant families toward the service. For example, advanced care planning involving family members could be a possible way to engage family members in PC decision making. Supportive interventions, e.g., providing knowledge, aimed at patients and their family members might improve knowledge and increase awareness among South Asian migrant families of PC. Knowledge gained from this review could be implemented with other ethnic minority groups. **Abstract:** <http://bit.ly/2YKWahw>

REHPA
The Danish Knowledge Centre
for Rehabilitation and
Palliative Care

Spiritual coping and psychological symptoms as the end approaches: A closer look on ambulatory palliative care patients

PSYCHOLOGY, HEALTH & MEDICINE | Online – 9 July 2019 – Palliative care (PC) providers must seek to improve quality of life despite their patients' life-threatening diseases, based on the concept of total pain, which includes physical, psychological and spiritual pain. Understanding the relationship between spiritual coping and psychological symptoms (especially depressive symptoms) could help healthcare teams better address patients' needs. This study found a significant relationship between psychological pain and negative spiritual coping mechanisms. **Abstract:** <http://bit.ly/2Y3gRrU>

Palliative care ethical guidelines to assist healthcare practitioners in their treatment of palliative care patients

SOUTH AFRICAN JOURNAL OF BIOETHICS & LAW, 2019;12(1):14-18. At the request of the Health Professions Council of South Africa (HPCSA), draft ethical guidelines on palliative care (PC) have been produced, to assist healthcare practitioners in their treatment of PC patients. These have been submitted to the HPCSA, which has circulated them for comment by the boards and other relevant stakeholders. This article provides a wider audience, including healthcare practitioners and patients involved in PC, an opportunity to comment on the draft guidelines. **Abstract:** <http://bit.ly/2xAsqYG>

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

What young people need when a family member dies of cancer

SUPPORTIVE CARE IN CANCER | Online – 5 July 2019 – This study uses the newly developed Bereaved Cancer Needs Inventory to identify the unmet psychosocial needs of adolescents and young adults who have experienced the death of a parent or sibling to cancer, and to explore the relationship between unmet needs and psychological distress. 278 bereaved offspring and 38 bereaved siblings (12-25 years) completed the 58-item Bereaved Cancer Needs Inventory and the Kessler psychological distress scale. Bereaved offspring reported 27 unmet needs on average; 94% indicated at least one unmet need, with 80% indicating 10 or more needs. Bereaved siblings reported 23 unmet needs on average; 97% indicated at least one unmet need, with 68% indicating 10 or more needs. For both bereaved offspring and siblings, the needs for “support from other young people” and “time out and recreation” were most frequently reported as unmet. Approximately half of all participants reported high to very high levels of psychological distress. **Abstract (w. list of references):** <http://bit.ly/32c6np8>

Related

- *DEATH STUDIES* | Online – 11 July 2019 – ‘**Developing a practice-based research agenda for grief and bereavement care.**’ Grief and bereavement care providers were invited to participate in a three-phase Delphi study to create expert consensus on the top priorities for grief and bereavement research. A total of 140 participants completed Phase 1, 84 completed Phase 2, and 70 completed Phase 3. The top 10 research priorities form the basis of a practice-based research agenda for grief and bereavement care to enable researchers to respond to key issues in grief and bereavement care that will ultimately improve the lives of bereaved people. **Abstract:** <http://bit.ly/2xJUAAs>

Content analysis of advance directives completed by patients with advanced cancer as part of an advance care planning intervention

SUPPORTIVE CARE IN CANCER | Online – 5 July 2019 – This study provides the insight that being independent, maintaining a normal life, having meaningful relations and being free from pain are important topics in advance directives (ADs) for patients with advanced cancer in... A more comprehensive AD, meaning an AD that includes exploratory sections and preferences, provides healthcare professional and relatives a better perspective of the most important values of patients at the end of their life, and, therefore, offers an opportunity to improve the guidance of the healthcare professional (HCPs). Having a conversation to understand the reasoning behind indicated preferences remains essential for relatives and HCPs to make decisions that are in line with the preferences of the patient. **Full text:** <http://bit.ly/2LdsxCv>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 12 July 2019 – ‘**Hospital and health system policies concerning the California End of Life Option Act.**’ The End of Life Option Act (EoLOA) legalized physician aid in dying for competent, terminally ill Californians in 2016. The law allows clinicians, hospitals, and health systems to decide whether to participate. About 4 in 10 California hospitals permit the EoLOA, but little is known about their approaches and concerns. Every surveyed hospital had established a position on the EoLOA. Among hospitals permitting EoLOA, 38% required safeguards not required in the law, 87% provided for referral to another provider if the patient’s physician did not participate, and 65% counseled staff, if needed. Among hospitals not permitting the EoLOA, nearly all allowed providers to follow patients choosing to pursue the EoLOA elsewhere and most permitted a provider to refer to another provider or system. Most hospitals expressed concerns about implementation of the EoLOA and interest in sharing promising practices. This survey of California hospitals demonstrates considerable heterogeneity in implementing the EoLOA. **Abstract:** <http://bit.ly/30x4QIQ>
- *NURSING INQUIRY* | Online – 4 July 2019 – ‘**Shades of gray: Conscientious objection in medical assistance in dying.**’ With the advent of legalized medical assistance in dying (MAiD) in Canada in 2016, nursing is facing intriguing new ethical and theoretical challenges. Among them is the concept of conscientious objection, which was built into the legislation as a safeguard to protect the rights of healthcare workers who feel they cannot participate in something that feels morally or ethically wrong. The authors consider the ethical complexity that characterizes nurses’ participation in MAiD and propose strategies to support nurses’ moral reflection and imagination as they seek to make sense of their decision to participate or not. Deconstructing the multiple and sometimes conflicting ethical and professional obligations inherent in nursing in such a context, the authors consider ways in which nurses can sustain their role as critically reflective moral agents within a context of a relational practice, serving the diverse needs of patients, families, and communities, as Canadian society continues to evolve within this new way of engaging with matters of living and dying. **Full text:** <http://bit.ly/2FWonu8>
- *PALLIATIVE MEDICINE* | Online – 8 July 2019 – ‘**A qualitative study of physicians’ conscientious objections to medical aid in dying.**’ Under Quebec’s Act respecting end-of-life care, physicians may refuse to provide medical aid in dying because of personal convictions, also called conscientious objections. Before legalisation, the results of the authors’ survey showed that the majority of physicians were in favour of medical aid in dying (76%), but one-third (28%) were not prepared to perform it. After 18 months of legalisation, physicians were refusing far more frequently than the pre-Act survey had anticipated. The majority of physicians who refused to participate did not oppose medical aid in dying. The reason most often cited is not based on moral and religious grounds. Rather, the emotional burden related to this act and the fear of psychological repercussions were the most expressed motivations for not participating in medical aid in dying. **Abstract:** <http://bit.ly/2XDfocr>

Publishing Matters

Why India is striking back against predatory journals

NATURE | Online – 2 July 2019 – According to 2015 estimates, more than 8,000 predatory journals churn out more than 400,000 items a year, and India – which has also seen a spurt in high-quality scientific publications – contributes more than one-third of the articles in predatory publications. Last month, India launched its latest salvo against the “pay and publish trash” culture that sustains predatory journals. Over several months, more than 30 organizations representing universities and academic disciplines have vetted journals to release a reference list of respectable titles. Fending off the attack of trash science will be a long battle. Predatory journals have severely compromised scientific scholarship. They collect fees, but do not perform peer review or other promised services. India’s experience so far shows both what makes an academic enterprise vulnerable to predatory publishers, and the coordinated efforts necessary to thwart them. **Full text:** <https://go.nature.com/2S00qqC>



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