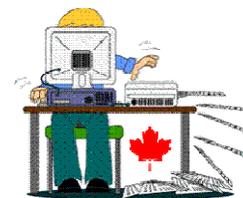


Media Watch...

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

Although spiritual care is a core element of end-of-life (EoL) care for older people, a clear-cut definition of spirituality has not been established yet. It remains unclear how spirituality is perceived by healthcare professionals and how spiritual care is delivered at the EoL.

'Spirituality in older men living alone near the end-of-life' (p.14), in *Nagoya Journal of Medical Science*.

Canada

"Bad death" hurts more for loved ones left behind: Study

FOLIO (University of Alberta) | Online – 2 December 2019 – Grief is difficult to bear, but when you believe your loved one died badly, it's even worse, according to a new University of Alberta study.¹ "It could be dying in pain or with other unrelieved symptoms like nausea, or they wanted to die at home but couldn't; there are many ways in which they could feel it is not a good death," said Donna Wilson, a nursing professor who led the study. "The family is left with the memories of what did or didn't happen, and what should have happened, when a person was dying." Wilson and her research team surveyed 151 people for the study, with half of them indicating they had high levels of grief months or even years after the death of a loved one. A little more than half, 55%, rated the death of their loved one as more bad than good. The research ... points to a troubling trend as Canada's population ages, said Wilson. The fact that more than

half the people in the survey felt their loved ones had bad deaths "tells all of us – nurses, other healthcare providers and the public – that we have a long way to go to improve our care of the dying. This care has a major impact on those who are left to grieve," said Wilson. The findings build on a 2017 study she led that showed 96% of Canadian respondents in a survey had experienced bereavement grief, often multiple times, and 78% were actively grieving the death of a loved one.² <http://bit.ly/2Peoag2>

Specialist Publications

'A public health approach to palliative care in the Canadian context' (p.7), in *American Journal of Hospice & Palliative Medicine*.

1. 'Is the bereavement grief intensity of survivors linked with their perception of death quality?' *International Journal of Palliative Nursing*, published online 22 August 2019. **Abstract:** <http://bit.ly/33IkFNN>
2. 'Bereavement grief: A population-based foundational evidence study,' *Death Studies*, published online 9 January 2018. **Abstract:** <http://bit.ly/2RrrAZB>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *The Vancouver Sun* – 5 December 2019 – ‘**Fraser Health wants meeting with hospice over decision to ban assisted dying.**’ Fraser Health is seeking a meeting with the newly elected Delta Hospice Society board over its decision to not provide assisted dying at its Ladner facility. In a prepared statement, Fraser Health said it was seeking a meeting to “discuss our concerns” with the board’s decision. The newly appointed hospice society president, Angelina Ireland, told staff and volunteers at its Irene Thomas Hospice that the board had repealed a recent decision by the old board to allow medical assistance in death (MAiD) at the facility. This goes against Fraser Health policy that anyone staying in one of its non-faith-based hospice facilities has the right to access MAiD. Fraser Health funds 10 hospices, that includes seven of its own facilities and three under contract – including Irene Thomas. The health authority provides \$1.3 million a year to the society to help operate the 10-bed Irene Thomas Hospice... The society has had issues with allowing MAiD at the hospice since it became legal in 2016. While Fraser Health states that anyone in its non-faith-based hospices must have access to MAiD, the hospice has refused to abide. <http://bit.ly/33WcUnA>

U.S.A.

U.S. ranks high in palliative care access

HOSPICE NEWS | Online – 6 December 2019 – The U.S. is in the top tier compared to other nations in terms of patient access to palliative care (PC), though much of the country remains underserved despite rising demand. Only 14% of the global population has access to PC at the highest level of provision, with the highest concentrations in European countries...¹ Global demand for PC is expected to rise by 87% by 2060 due to the aging population and associated prevalence of chronic health conditions... Researchers conducted an electronic survey of experts in 198 countries on 10 indicators of PC access. Of those, 30%, including the U.S., were classified as having PC at an advanced state of integration, the highest level category used in the research. No access to PC was the lowest category, accounting for 24% of surveyed countries. The research relied on 2017 data. <http://bit.ly/34XrZ9O>

Specialist Publications

‘**Characteristics of hospice and palliative care programs in U.S. prisons: An update and 5-year reflection**’ (p.6), in *American Journal of Hospice & Palliative Medicine*.

‘**Trends in hospital-based specialty palliative care in the U.S. from 2013 to 2017**’ (p.11), in *JAMA Network Open*.

‘**Case management for Southwestern Hospice Organization: Process improvement plan**’ (p.12), in *Journal of Hospice & Palliative Nursing*.

‘**Results from a survey of American Geriatrics Society members’ views on physician-assisted suicide**’ (p.17), in *Journal of the American Geriatrics Society*.

1. ‘Mapping levels of palliative care development in 198 countries: The situation in 2017,’ *Journal of Pain & Symptom Management*, published online 21 November 2019. [Noted in 25 November 2019 issue of *Media Watch* (#641, p.12)] **Full text:** <http://bit.ly/2s1eAin>

Bringing palliative care to underserved rural communities

HEALTH AFFAIRS, 2019;38(12):1971-1975. Palliative care (PC) remains scarce among Alabama’s smallest hospitals, offered at only five of twenty-seven (18.5%) of hospitals with fewer than 50 beds versus nearly all hospitals with 300-plus beds, according to the recent Center to Advance Palliative Care report.¹ The national pattern is similar: About one-third of small hospitals incorporate palliative services, versus 93.7% of those with more than 300 beds. These patients might suffer needlessly at home without ade-

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quate symptom relief and other mental health support, or bounce in and out of their nearby rural hospital, using it more as a primary care clinic, says Marie Bakitas, associate director of the University of Alabama Center for Palliative & Supportive Care. Or, as their condition worsens, they might get transferred to a larger hospital far from home. <http://bit.ly/2DMjJ0x>

1. 'America's Care of Serious Illness: 2019 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals,' Centre to Advance Palliative Care & National Palliative Care Research Centre, September 2019. [Noted in 30 September 2019 issue of Media Watch (#633, p.3)] **Download/view at:** <http://bit.ly/2lrJOWl>

N.B. The focus of the December issue of *Health Affairs* is rural health. Contents page: <http://bit.ly/34PtarW>

Noted in Media Watch 4 November 2019 (#638, p.4):

- **FORBES** | Online – 28 October 2019 – '**The special challenges of nearly 11 million seniors who live in rural communities.**' According to a new report by the U.S. Census bureau, about 10.6 million older adults live in rural communities – roughly one quarter of all seniors.¹ About 17.5% of rural residents are over 65, while only about 14% of urban residents are older adults. Three-quarters of rural older adults live in the South and Midwest, but in states such as Maine and Vermont almost two-thirds of seniors live in rural communities. In many rural areas, there are no Medicare- or Medicaid-certified home care agencies or hospice programs. Thus, providers must travel many miles to deliver care, if it is available at all. <http://bit.ly/36gn05f>

1. 'The Older Population in Rural America: 2012-2016 American Community Survey Reports,' U.S. Census Bureau, September 2019. **Download/view at:** <http://bit.ly/32YKbPn>

N.B. Selected articles on the provision and delivery of hospice and PC services in rural America noted in 7 October 2019 issue of Media Watch (#634, p.2).

Hospices embrace direct-to-consumer marketing

HOSPICE NEWS | Online – 1 December 2019 – In an increasingly competitive digital marketplace, hospice providers are embracing direct-to-consumer marketing tactics to include patients and families in their outreach. Among the drivers of this trend is the need to educate the public about the nature of hospice and palliative care (PC). Most people in the U.S. have a low level of awareness of these services, with more than 30% of participants agreeing with statements such as "hospice care is only about death" and "hospice care is seen as giving up," a 2017 study ... found.¹ Palliative and hospice care education initiatives are necessary to boost awareness of and reduce misperceptions about these services, the study concluded. Breaking down public misperception has been a long-standing struggle in hospice and PC. While most providers in service industries can speak directly to their consumers' interests, the very nature and complexity of hospice services makes marketing to prospective patients and their families a

significant challenge to overcome and must be treated with a high degree of sensitivity. Marketing involves building consumer trust and loyalty, but with a delicate subject matter and the obstacles of misinformation, this is easier said than done for hospices. <http://bit.ly/2P0JyPE>

Hospices rebrand to shake stigma, reflect scope of service

HOSPICE NEWS | Online – 2 December 2019 – As hospices nationwide develop new services to engage patients further upstream, some are rebranding to reflect their expanded scope and to avoid the word "hospice" in their company names, hoping to ameliorate patients' anxiety about end-of-life care. Rebranding is part of a growing trend in hospice care that sees providers diversifying their services to better assist patients, but also to change the general perception of hospice care. <http://bit.ly/33Q0JZK>

1. 'Awareness and misperceptions of hospice and palliative care: A population-based survey study,' *American Journal of Hospice & Palliative Medicine*, published online 20 June 2017. [Noted in 26 June 2017 issue of Media Watch (#518, p.6)] **Full text (via PubMed):** <http://bit.ly/2U2dXCI>

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Noted in Media Watch 11 November 2019 (#639, p.5):

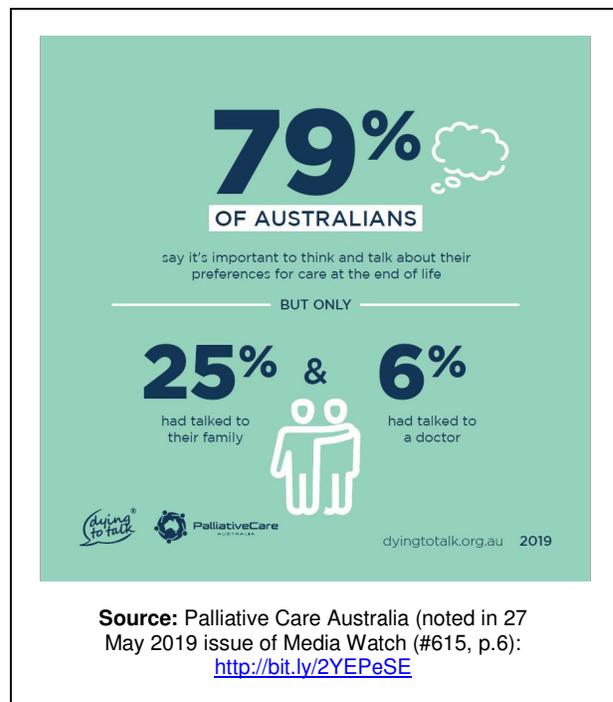
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2019 – ‘**Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: A scoping literature review.**’ The majority of studies reported the public having poor knowledge and awareness of palliative care (PC) over the past 16 years. Top characteristics associated with increased levels of knowledge and/or awareness of PC included women, age 40+, experience with a close friend and/or relative requiring PC, and working in healthcare and/or PC. Participants commonly received information about PC from the media, having a close friend or relative requiring PC, and working in a healthcare setting. **Abstract:** <http://bit.ly/2PTjKa4>

N.B. Additional articles on public awareness, knowledge, and perceptions of PC noted in this issue of Media Watch.

International

Nearly a third of advance care directives are invalid

AUSTRALIA | *Talking Aged Care* – 3 December 2019 – A nationwide study from Advance Care Planning Australia (ACPA), a national program empowering consumers to prepare for important healthcare decisions in the future, has found nearly a third of advance care directives (ACDs) audited in residential aged care facilities around the country were invalid.¹ The research uncovered 30% of ACDs of residents in nursing homes had been completed by another person, such as a family member, on behalf of a person that was no longer competent; around 68% had instructions for withholding life-sustaining treatment, like tube feeding or intravenous antibiotics. ACPA’s research has found that advance care planning is very low in Australia, with 75% of people aged 65 and over not completing an ACD. This number is similar for residents in nursing homes with 62% of residents over 65 not having a completed ACD on their health record. ACPA believes that with such a large ageing Australian population, there is a growing expectation that people will continue to make their own medical choices well into their senior years. ACPA has released ten recommendations to improve awareness of the importance of ACDs. <http://bit.ly/38bAlan>



1. 'ACPA Position Statement: Advance care directives within community and residential aged care,' Advance Care Planning Australia, December 2019. <http://bit.ly/2qshJHO>

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Noted in Media Watch 25 February 2019 (#603, p.10):

- *INTERNAL MEDICINE JOURNAL* | Online – 20 February 2019 – ‘**Prevalence of advance care directives in the community: A telephone survey of three Australian States.**’ Despite long-standing efforts to increase advance care planning, community prevalence of advance care directives (ACDs) remains low, particularly for instructional ACDs. This study [i.e., a telephone survey of adults living in New South Wales, Victoria and Queensland] found some different predictors for instructional ACDs compared with appointing ACDs, and also a potential role for experiential factors in triggering uptake. These findings suggest supplementing general community awareness campaigns with more nuanced and targeted efforts to improve ACD completion. **Abstract:** <http://bit.ly/2U23qTT>

A Field Manual for Palliative Care in Humanitarian Crises

EUROPEAN ASSOCIATION OF PALLIATIVE CARE (EAPC) BLOG | Online – Accessed 2 December 2019 – Recently, there has been increasing recognition of the importance of integrating palliative care (PC) into humanitarian aid. This is reflected in a growing number of journal articles and position papers on this topic, most notably the World Health Organization guide.¹ This increasing recognition is in part a reflection of the growth of PC as a medical subspecialty; it also reflects the increasing understanding that the goal of humanitarian aid is not simply to save lives, but also to alleviate suffering. This latter point cannot be overstated: when the primary focus of aid efforts remains simply and solely the saving of lives (which, of course, is a worthy goal), those efforts risk failing in the equally important, and morally and ethically compelling, goal of addressing suffering. Additionally, there may well be a “trickle-up” effect – that is, by integrating principles of PC into the fundamental approach to all patients, starting from the moment of triage, overall care improves across the board, regardless of outcome. This includes better overall symptom management, better communication (between clinicians and patients and families as well as among clinicians themselves), and improved staff resilience. Simply put, integrating principles of PC into the care of

all patients means better overall patient care and an improved healthcare system. Currently, there are not enough formally trained and certified PC providers to staff every humanitarian aid mission in the world, nor does that solution make the most sense. **Download/view introduction to manual at:** <http://bit.ly/2YcNjFJ>

Specialist Publications

‘**Palliative sedation: A safety net for the relief of refractory and intolerable symptoms at the end of life**’ (p.7), in *Australian Journal of General Practice*.

‘**Palliative care medical student education: A cross-sectional medical school survey in mainland China**’ (p.8), in *BMJ Supportive & Palliative Care*.

‘**The involvement of volunteers in palliative care and their collaboration with healthcare professionals: A cross-sectional volunteer survey across the Flemish healthcare system (Belgium)**’ (p.11), in *Health & Social Care in the Community*.

‘**Indian Council of Medical Research releases draft position paper on do not attempt resuscitation**’ (p.14), in *Medical Dialogues*.

1. ‘Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises,’ World Health Organization, October 2018. [Noted in 1 October 2018 issue of Media Watch (#583, p.6)] **Download/view at:** <http://bit.ly/2T4AScC>

N.B. See ‘Palliative care as a basic healthcare right: A new consensus within the humanitarian community,’ a recent posting on the EAPC blog at: <http://bit.ly/35Z11yR>

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Noted in Media Watch 21 October 2019 (#636, p.8):

- *BRITISH MEDICAL JOURNAL* | Online – 14 October 2019 – ‘**Palliative care in humanitarian crises...**’ Recently there has been renewed interest in how to best integrate palliative care (PC) into aid efforts during humanitarian crises. The range of people who would stand to benefit from this is broad. It includes people with life-limiting and complex chronic conditions who may have benefitted from PC even before a disaster. Then there are those with potentially life-limiting conditions that are a result of the crisis... PC may include support for family members and for medical providers who are struggling with the burden of care and loss. The recognition that PC may have an important role in relief efforts is long overdue, but is gradually starting to gain traction. **Full text:** <http://bit.ly/2MfqIEg>

Noted in Media Watch 9 September 2019 (#630, p.9):

- *MEDICAL JOURNAL OF AUSTRALIA*, 2019;211(5):201-203. ‘**Integrating palliative care and symptom relief into responses to humanitarian crises.**’ The medical and moral imperative that palliative care (PC) be integrated into standard responses to humanitarian crises (HC) can be fulfilled by basic training and an essential set of medicines, equipment, social support and protocols. Humanitarian crises often cause both extensive loss of life and widespread suffering. Yet HC response virtually never fully integrates PC, the discipline devoted to preventing and relieving suffering. Recently, the World Health Organization recognised the necessity of integrating PC and symptom relief into responses to HC of all types and published a guide to this integration. **Abstract:** <http://bit.ly/2ZGvFcJ>

N.B. Additional articles on PC in humanitarian crises noted in this issue of Media Watch.

Specialist Publications

Characteristics of hospice and palliative care programs in U.S. prisons: An update and 5-year reflection

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 6 December 2019 – Individuals with terminal illness are dying behind bars and many state prison administrators have incorporated on-site hospice and palliative care (PC) services. Little is known, however, about these programs since a 2010 study of prison hospice characteristics.¹ A cross-sectional survey was sent to representatives of all known prisons offering hospice and PC programs and services. Questions were drawn from an earlier iteration regarding interdisciplinary team (IDT) membership, training length and topics, peer caregivers, visitation policies, bereavement services, perceived stakeholder support, and pain management strategies. Additional questions were added such as estimated operational costs, peer caregiver input in patient care, and the strengths and weaknesses of such programs. Frequency distributions were calculated for all study variables. Responding representatives indicated IDTs remain integral to care, peer caregivers continue to support dying patients, and perceived public support for these programs remains low. Reduced enthusiasm for

the programs may negatively influence administrative decision-making and program resources. Further, peer caregiver roles appear to be changing with caregivers charged with fewer of the identified tasks, compared with the 2010 study. **Abstract:** <http://bit.ly/2D0p3Ay>



Prison Hospice: Backgrounder

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 from the Palliative Care Network website at: <http://bit.ly/2RdegnL>

Photo: Lori Waselchuk. Philadelphia, PA

1. ‘Characteristics of prison hospice programs in the U.S.,’ *American Journal of Hospice & Palliative Medicine*, 2011;28(4):245-252. **Abstract:** <http://bit.ly/2OWLhXx>

A public health approach to palliative care in the Canadian context

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 4 December 2019 – In Canada, delivery and access to palliative care (PC) has been fraught with challenges including differential availability of services based on geography, funding, language, and socioeconomic status. Many groups, including the World Health Organization, have advocated for a public health approach to PC as an antidote to fragmented service delivery. Multiple scholars, academics, and public health advocates have suggested that a public health approach to PC can help with issues of access, equity, and cost. This commentary explores potential reasons why a public health approach to PC has not been adopted in the Canadian context and why this is an opportune time to consider this policy innovation. The Compassionate Communities concept is discussed as a potential solution to a public health approach to PC delivery. **Abstract:** <http://bit.ly/2Lm5cwJ>

N.B. Selected articles on access to PC in Canada noted in 2 December 2019 issue of Media Watch (#642, pp.1-2).

Noted in Media Match 25 February 2019 (#603, p.12):

- *PALLIATIVE CARE: RESEARCH & TREATMENT* | Online – 20 February 2019 – ‘**Palliative care and public health: An asymmetrical relationship?**’ The authors develop a range of critical perspectives on the relationship between public health (PH) and palliative care by scrutinising its claims of utility and effectiveness and questioning the strength of the interdisciplinary interaction between the two disciplines. They see their relationship in a “cross disciplinary” context which is still largely symbolic and tactical in nature. The authors considers the significance of these insights for policy and practice, with two possible scenarios. If the use of PH is essentially figurative and its resources are not unique, the particular and exclusive use of the term becomes insignificant. **Full text:** <http://bit.ly/2Xhk1oG>

Noted in Media Watch 4 February 2019 (#600, p.9):

- *HEALTH PROMOTION INTERNATIONAL* | Online – 27 January 2019 – ‘**Unpacking “the cloud.”: A framework for implementing public health approaches to palliative care.**’ The Health Impact Change Model (HICM) was developed to unpack the complexities associated with the implementation and evaluation of a Canadian compassionate communities intervention. The HICM offers utility for citizens, leaders and decision-makers who are engaged in the implementation of population health level strategies or other social approaches to care, such as compassionate cities and age or dementia-friendly communities. The HICM’s concepts can be adapted to address a community’s healthcare context, needs, and goals for change. **Abstract:** <http://bit.ly/2RrPpgd>

Palliative sedation: A safety net for the relief of refractory and intolerable symptoms at the end of life

AUSTRALIAN JOURNAL OF GENERAL PRACTICE, 2019;48(12). Primary care doctors may be involved in multidisciplinary team meetings discussing palliative sedation (PS) for their patients in a hospital setting. Alternatively, family members whose loved ones have required PS may need to be followed up and monitored for psychological and moral distress, which is why it is important for general practitioners to be aware of this therapy. PS is complex. There is currently no Australian PS framework for primary care doctors to apply in different clinical settings (e.g., home, residential homes and rural/remote areas). Implementation in rural settings and other low-resource environments would require careful adaptation of the current guidelines including reference to the potential role of telehealth. PS is an important, evidence-based, effective therapy. **Full text:** <http://bit.ly/2rQgm5U>

N.B. Additional articles on PS noted in 11 November 2019 issue of Media Watch (#639, p.10).



Closing the Gap Between Knowledge & Technology
<http://bit.ly/2DANDFB>

Critical nursing and healthcare aide behaviors in care of the nursing home resident dying with dementia

BMC NURSING | Online – 29 November 2019 – The critical behaviors described by nurses and health-care aides in this study provides emerging evidence of best practices in care of those with dementia and their families, particularly near the end of life. All of these behaviors served to achieve the overarching goal of resident comfort – a salient outcome articulated in the European Association for Palliative Care white paper defining optimal palliative care (PC) in older people with dementia¹ and the World Health Organization's global perspective on PC. **Full text:** <http://bit.ly/2LkgZeO>

1. 'White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,' *Palliative Medicine*, published online 4 July 2013. [Noted in 8 July 2013 issue of *Media Watch* (#313, p.10)] **Full text:** <http://bit.ly/2P53RLM>

Paramedic information needs in end-of-life care: A qualitative interview study exploring access to a shared electronic record as a potential solution

BMC PALLIATIVE CARE | Online – 5 December 2019 – The findings of this study provide useful insight for professionals within and beyond the U.K., as healthcare systems around the world increasingly recognise the importance of advance care planning (ACP) in end-of-life (EoL) care and the need to implement electronic patient records to facilitate the delivery of appropriate care. This study has identified a need, and strong desire, for improved access to accurate and in-date ACP documentation for paramedics attending patients at EoL. Access to an electronic palliative care coordination system (EPaCCS) offers a potential solution, however, several barriers need to be addressed for this to be successful in practice. Further research is needed to support the development and implementation of EPaCCS for paramedics, and to evaluate its usefulness in practice. As the success of such a record depends on the quality and consistency of the information uploaded, additional research exploring, and training provided to improve, professional recording practices in EoL care is vital to aid the establishment of an effective record. **Full text:** <http://bit.ly/34Ydwua>

N.B. Selected articles on the role of paramedics in palliative and EoLC noted in 2 December 2019 issue of *Media Watch* (#642, p.14).

Phase I cancer trials: A qualitative study of specialist palliative care

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 29 November 2019 – In recent years, a simultaneous care model for advanced cancer patients has been recommended meaning that palliative care (PC) services are offered throughout their cancer journey. To inform the successful adoption of this model in a phase I trial context, the study aimed to explore patients' care needs and their perceptions of specialist PC. Despite reporting considerable physical and psychological impacts from cancer and cancer treatment, participants did not recognise a need for specialist PC support. Understanding of the role of specialist PC was largely limited to end-of-life care. There was perceived conflict between considering a phase I trial and receiving specialist PC. Participants felt specialist PC should be introduced earlier and educational resources developed to increase patient acceptability of PC services. Developing a specific educational resource about specialist PC for this population would help overcome barriers to engaging with a simultaneous care model. **Abstract:** <http://bit.ly/2Rhw6K5>

Palliative care medical student education: A cross-sectional medical school survey in mainland China

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 29 November 2019 – According to the 2015 Quality of Death Index, China ranks 71st in terms of quality of palliative care (PC) out of 80 countries.¹ Lack of PC education for health professionals is regarded as largely responsible. The majority of responders acknowledged that PC was very important, but there was an apparent contradiction between the high percentage who thought PC was important and the low rate of implementing PC education. Deans reported

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that the most significant barrier to increased teaching of PC in the undergraduate curriculum was that the medical curriculum dictated by the Ministry of Education does not require it. Integrating PC content into the undergraduate curriculum is a major endeavour, which depends on government guidelines. Most of the deans did not recognise PC as an independent discipline, so where it is available, it tends to be integrated into other courses rather than creating new courses devoted to PC. Economic factors such as Gross National Income *per capita* have been observed to be significantly associated with levels of PC development across a range of country settings. China is no exception, and this explains the better level of PC education in the eastern region of China, which has a higher level of economic development compared with the central and western regions. **Full text:** <http://bit.ly/2P710oi>

1. '2015 Quality of Death Index: Ranking Palliative Care Across the World,' *The Economist Intelligence Unit*, October 2015. [Noted in 12 October 2015 issue of *Media Watch* (#431, p.6)] **Download/view at:** <http://bit.ly/30YoDkI>

Noted in *Media Watch* 18 November 2019 (#640, p.13):

- *MEDICINE*, 2019;98(45):e17683. '**Knowledge and attitudes toward end-of-life care among community healthcare providers and its influencing factors in China: A cross-sectional study.**' Community healthcare provider (CHP) attitudes toward end-of-life care (EoLC) were predicted by death attitudes, working experience, experiences of the death of relatives, and experiences of caring for the dying. This suggested that CHP attitudes toward EoLC were influenced by a variety of variables that were not included in this study. Public's insufficient knowledge of EoLC, imperfect medical insurance system, imperfect policies, laws and systems of palliative care, and the lack of localized end-of-life models also influenced CHP attitudes toward EoLC. **Full text:** <http://bit.ly/36SV1sG>

N.B. Additional articles on PC in China noted in 29 July 2019 issue of *Media Watch* (#624, p.11).

Shared decision-making: Why the slow progress?

BRITISH MEDICAL JOURNAL | Online – 5 December 2019 – Shared decision-making occurs when clinicians and patients work together to select tests, treatments, management, or support packages, based on clinical evidence and patients' informed preferences. It involves providing evidence based information about options, outcomes, and uncertainties, together with counselling and a system for recording and implementing patients' informed preferences. Shared decision-making has its roots in the ethical principles underpinning clinical practice. In the U.K. it is included in the National Health Service (NHS) Constitution and is a requirement of the doctors' regulator the General Medical Council, and it is recommended as usual practice by NHS England and in guidelines by the National Institute for Health & Care Excellence. Every year from 2009, the healthcare services regulator the Care Quality Commission (CQC) has asked hospital inpatients whether they were involved as much as they wanted to be in decisions about their care and treatment. In 2018 just over 50% of 75,000 respondents answered, "Yes, definitely," and the pace of any progress

seems glacial: about 25% of patients agreed when the CQC asked whether doctors had talked in front of them as if they weren't there. **Full text:** <http://bit.ly/2PhBHxa>



Media Watch: The Homeless

The plight of the homeless is gaining increased attention, indicative of worldwide efforts to address the needs of this particularly vulnerable population. In Canada alone, more than 235,000 people experience homelessness in a year. Selected articles from past issues of *Media Watch* are noted in the December issue of the Association's newsletter (scroll down to 'Media Watch: The Homeless'): <http://bit.ly/2OVQyP3>

Why many oncologists fail to share accurate prognoses: They care deeply for their patients

CANCER | Online – 27 November 2019 – Although most patients with cancer wish to know their prognosis, oncologists fail to initiate timely and repeated discussions of prognosis with their patients. This gap, rooted in physicians' deep care and optimism for their patients, may be narrowed by three complimentary approaches: asking simple questions to open up the discussion, assessing patient preferences, and using prognostic tools that can help with the accuracy of prognoses. **Abstract:** <http://bit.ly/33BJGud>

Noted in Media Watch 4 November 2019 (#638, p.8):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 30 October 2019 – **“Farewell” to prognosis in shared decision-making.** Whether because of a cultural pattern or personal preference, palliative care clinicians encounter persons approaching the end of life (EoL) who wish to limit or forego prognostic information relating to their situation. The ordinary expectation for EoL shared decision-making with a capable person is clinician disclosure of the best effort at prognostic assessment. For the clinician, a person's choice to modify information disclosure and participation in shared decision-making represents a significant challenge of balancing key ethical principles of intervention with tolerance and compassion for these different preferences. **Abstract:** <http://bit.ly/2Nv06P5>

Noted in Media Watch 30 September 2019 (#633, p.11):

- *PALLIATIVE MEDICINE* | Online – 28 September 2019 – **‘Predicting survival in patients with advanced cancer in the last weeks of life: How accurate are prognostic models compared to clinicians’ estimates?’** The authors compared the prognostic accuracy of Palliative Performance Scale, Palliative Prognostic Index, Palliative Prognostic Score, and clinician prediction of survival in this setting. A total of 204 patients were included with a median overall survival of 10 days... In patients with advanced cancer with days of survival, clinician prediction of survival and Palliative Performance Scale alone were as accurate as Palliative Prognostic Score and Palliative Prognostic Index. **Abstract:** <http://bit.ly/2oc9sq1>

A systematic review of the psychometric properties of death anxiety self-report measures

DEATH STUDIES | Online – 6 December 2019 – Although the investigation of death anxiety in clinical populations is relatively recent, the death anxiety literature as a whole has a longer history evidenced by the number of instruments developed to measure this construct. This systematic review aimed to evaluate the evidence supporting the psychometric properties of self-report death anxiety measures. Overall findings suggest that additional research is needed to establish the psychometric adequacy of death anxiety instruments, especially given increased utilization of these measures in both clinical and research settings. **Abstract:** <http://bit.ly/2YAMx5T>

General practitioners’ considerations when deciding whether to initiate end-of-life conversations: A qualitative study

FAMILY PRACTICE | Online – 4 December 2019 – End-of-life (EoL) discussions often are not initiated until close to death, even in the presence of life-limiting illness or frailty. Previous research shows that doctors may not explicitly verbalize approaching EoL in the foreseeable future, despite shifting their focus to comfort care. This may limit patients' opportunity to receive information and plan for the future. General practitioners (GPs) have a key role in caring for increasing numbers of patients approaching EoL. Australian GPs [i.e., study participants] believe they have a responsibility to initiate EoL conversations, and identify several triggers to do so. Some also describe caution in raising this sensitive topic, related to patient, family, cultural and personal factors. These findings enable the development of approaches to support GPs to initiate EoL discussions that are cognizant both of GPs' sense of responsibility for these discussions, and factors that may contribute to caution initiating them, such as anticipated patient response, cultural considerations, societal taboos, family dynamics and personal challenges to doctors. **Abstract:** <http://bit.ly/2RpDjl2>



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Related

- *FAMILY PRACTICE* | Online – 1 December 2019 – ‘**General practitioners’ practical approach to initiating end-of-life conversations: A qualitative study.**’ Participants described a nuanced and discretionary approach embedded within each doctor-patient relationship dynamic. GPs described EoL conversations as a process. This involved initially preparing the ground for the discussion by establishing strong doctor-patient relationships; gauging patients’ readiness to engage; and, managing time availability. Entry points to the conversation varied and could include responding to patient initiation, incorporation into routine care, raising discussions around prognosis or less directly discussing hypothetical deterioration or enquiring about patients’ views about death. **Full text:** <http://bit.ly/2qfGmaw>

Noted in Media Watch 4 November 2019 (#638, p.9):

- *BMC PALLIATIVE CARE* | Online – 31 October 2019 – ‘**Australian GPs’ perceptions of barriers and enablers to best practice palliative care: A qualitative study.**’ GPs reported difficulties with palliative care (PC) provision due to: 1) The complex and often emotional nature of doctor-family-interaction; 2) A lack of evidence to guide care; and 3) The need to negotiate roles and responsibilities within the healthcare team. GPs listed a number of strategies to help deal with their workload and to improve communication processes between healthcare providers. These included appropriate scheduling of appointments, locally tailored mentoring and further education, and PC guidelines which more clearly outline the roles and responsibilities within multidisciplinary teams. **Full text:** <http://bit.ly/2r3L4br>

N.B. A selection of articles noted in past issues of Media Watch on GPs and their key role in PC highlighted in November 2019 issue of the newsletter of the International Association for Hospice & Palliative Care (scroll down to ‘Media Watch: GPs & Quality Care’): <http://bit.ly/2NqALqN>

The involvement of volunteers in palliative care and their collaboration with healthcare professionals: A cross-sectional volunteer survey across the Flemish healthcare system (Belgium)

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 5 December 2019 – Volunteers occupy a specific space in the delivery of palliative care (PC), addressing specific aspects of care and providing a link between professional healthcare providers and informal care. Engaging and empowering these volunteers can be an important strategy to deliver more integrated and comprehensive PC. This study aims to describe volunteers’ involvement in the organisation of PC, collaboration with professionals and how they evaluate this. Overall, volunteer-professional collaboration was low, and mostly limited to information sharing. Dedicated PC volunteers collaborated extensively with nurses, often involving task coordination (46%). Ambiguity regarding tasks, agreements and/or rules (15%) and lack of information exchange (14%) were the most cited barriers to volunteer-professional collaboration. Many volunteers were open to stronger involvement in the organisation of care in PC services. Collaboration with professionals seemed lacking in width and depth. Particularly, nursing home volunteers indicated a desire and large potential for more involved and collaborative roles in PC provision. **Abstract:** <http://bit.ly/2PmZR9L>

Trends in hospital-based specialty palliative care in the U.S. from 2013 to 2017

JAMA NETWORK OPEN | Online – 6 December 2019 – Although palliative care (PC) historically focused on patients with cancer and those near the end of life, evidence increasingly demonstrates a benefit to patients with a broad range of serious illnesses and to those earlier in their illness. The field of PC has expanded and evolved rapidly, resulting in a need to characterize practice over time to understand whether it reflects evolving evidence and guidelines. This retrospective cohort study was ... at 88 US hospitals in which PC teams voluntarily participate in the Palliative Care Quality Network (PCQN), a national quality improvement collaborative. A total of 135,197 patients were referred to PCQN teams during the study period. Inpatient PC teams cared for an increasing percentage of patients with diagnoses other than cancer and saw more patients discharged alive, consistent with guidelines recommending specialty PC for all patients with serious illness earlier in their illnesses. Most patients with symptoms improved quickly. Variation in practice and outcomes among PCQN members suggests that there are opportunities for further improvements in care. **Full text:** <http://bit.ly/359QfD>

Do researchers in empirical ethics studies have a duty to act upon their findings? Case study in end-of-life decision-making

JOURNAL OF EMPIRICAL RESEARCH ON HUMAN RESEARCH ETHICS | Online – 28 November 2019 – The outlined empirical study on the decision-making process concerning the limitation of life-prolonging treatment (DLT) in patients with advanced cancer at a University hospital setting triggered some new questions for research ethics with respect to studies using empirical methods in medical ethics. The analyzed data of the study showed that less than half of the patients were involved in DLT. Deciding against cardiopulmonary resuscitation and transferal to the intensive care unit without informing and explaining it to the perfectly competent patient can be regarded as a violation of the ethical principle of respect for autonomy. This is what the embedded researcher witnessed throughout the study recruitment and data acquisition, as the non-involvement of patients was not just a result of the final data analysis. The ethical question raised in this situation was as follows: Does the embedded researcher have a moral duty to intervene when witnessing that ethical standards are not upheld? **Abstract:** <http://bit.ly/2sPfJKI>

Case management for Southwestern Hospice Organization: Process improvement plan

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 3 December 2019 – Studies have shown that registered nurses are inadequately prepared to care for patients requiring hospice and palliative care. Reasons include inadequate curriculum, along with a lack of structured education related to hospice/palliative care and symptom management, which includes inadequate education on delivering home-based hospice/palliative case management. Challenges at the Southwestern Hospice Organization are consistent with industry standards, evidenced by a high level of afterhours triage phone calls related to ineffective case management setup and delivery upon patient admission to hospice service. Many of these triage inquiries could be prevented with improved registered nurse case management education and subsequent execution. Through analyzing Southwestern Hospice Organization afterhours triage phone data, a deficiency in effective patient case management setup and delivery was defined. Best practices in hospice/palliative case management were then identified, and a quality improvement plan in the form of a nurse driven, hands-on, home hospice/palliative case management simulation was generated. Quality improvement for patient case management at the Southwestern Hospice Organization was the end goal. **Abstract:** <http://bit.ly/2OWk33h>

Using cards to facilitate conversations about wishes and priorities of patients in palliative care

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 25 November 2019 – To avoid discomfort, healthcare professionals may hesitate to pursue conversations about end of life with patients. Certain tools have the potential to facilitate smoother conversations in this matter. The objective [of this study] was to explore the experiences of patients in palliative care in using statement cards to talk about their wishes and priorities. Forty-six cards with statements of wishes and priorities were developed and tested for feasibility with 40 participants, who chose the 10 most important cards and shared their thoughts about the statements and conversation. One category describes practical aspects of using the cards including the relevance of the content and the process of sorting the cards. The second category describes the significance of using the cards including becoming aware of what is important, sharing wishes and priorities, and reflecting on whether wishes and priorities change closer to death. The cards helped raise awareness and verbalize wishes and priorities. All statements were considered relevant. The conversations focused not only on death and dying, but also on challenges in the participants' current life situation. **Abstract:** <http://bit.ly/2OefE4G>

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Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.18.

Noted in Media Watch 3 April 2017 (#506, p.12):

- *JOURNAL OF COMMUNITY HEALTH* | Online – 28 March 2017 – ‘**Clarifying values and preferences for care near the end of life: The role of a new lay workforce.**’ The authors report how trained community health workers used Go Wish cards to identify patients’ highest priority preferences and evaluated whether engaging in advance care planning conversations was associated with subsequent healthcare utilization. A one-year long, pre-post longitudinal design was used to evaluate an educational intervention using mixed-methods. The top-three card choices by patients was attending to spirituality and religious concerns, preparing for end of life, and maintaining personal wholeness. **Abstract (w. list of references):** <http://bit.ly/35Z11yR>

Telehealth acceptability for children, family, and adult hospice nurses when integrating the pediatric palliative inpatient provider during sequential rural home hospice visits

JOURNAL OF PALLIATIVE MEDICINE | Online – 5 December 2019 – Children in rural geographies are not universally able to access pediatric-trained palliative or hospice providers. Fifteen patients mean age of seven years were enrolled in this study. Family caregiver included 11 mothers (73%), 2 grandmothers (13%), and 2 fathers (13%). Fifteen nurses from nine hospice agencies participated. Twelve families (80%) included additional relatives by telehealth modality. Home distance averaged 172 miles with mean eight hours saved by accessing telehealth encounter. Visit content was primarily caregiver support, quality of life, goals of care, symptom management, and medication review. Telehealth acceptability improved between time points and was higher in family caregivers than hospice nurses. All children able to self-report stated a “like” for telehealth, citing six reasons such as “being remembered” and “medical knowledge and care planning.” Pediatric palliative telehealth visits partnered with in-person hospice nurse offer acceptable access to services, while extending support. **Abstract:** <http://bit.ly/38eGKqJ>

Noted in Media Watch 1 July 2019 (#620, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 25 June 2019 – ‘**Top ten tips palliative care clinicians should know about telepalliative care.**’ While additional data are needed, telepalliative care – the application of telehealth technologies to palliative care (PC) – may help address important challenges inherent to our specialty, such as geography and clinician staffing; the burden of traveling to brick-and-mortar clinics for patients who are symptomatic and/or functionally limited; and, the timely assessment and management of symptoms. This article, created by experts in telehealth and PC, provides a review of the current evidence for telepalliative care and potential applications and practical tips for using the technology. **Abstract:** <http://bit.ly/2iLi0M6>

Noted in Media Watch 30 April 2018 (#561, p.14):

- *PROGRESS IN PALLIATIVE CARE* | Online – 26 April 2018 – ‘**Mobile health technology and home hospice care: Promise and pitfalls.**’ With the increasing use of mobile devices (e.g., smart phones, tablets) in our everyday lives, people have the ability to communicate and share information faster than ever before. This has led to the development of promising applications aimed at improving health and healthcare delivery for those with limited access. This commentary outlines several potential benefits and pitfalls of incorporating mobile health applications into existing home hospice care while highlighting some of the relevant telemedicine work being done in the palliative and end-of-life care fields. **Abstract (w. link to references):** <http://bit.ly/2OX8NU4>

Noted in Media Watch 13 March 2017 (#503, p.12):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2017;19(2):130-139. ‘**Telehealth in palliative care: A systematic review of patient-reported outcomes.**’ Of 6 studies reporting qualitative outcomes, 3 reported 5 different methods for ensuring trustworthiness... Studies were notably diverse in terms of patient population, technology used, outcomes measures, and methodology. Results across studies were also variable. Methodological factors were major limitations. Recruitment problems, participant attrition, and lack of standardized outcomes measures impacted outcome assessment. Overall, research support for positive patient outcomes in palliative telehealth interventions was weak. All studies but one found positive results to support the intervention. **Abstract:** <http://bit.ly/2LxnfAh>

Indian Council of Medical Research releases draft position paper on do not attempt resuscitation

MEDICAL DIALOGUES | Online – 3 December 2019 – The main purpose of the position paper is to not prolong the suffering of the patient, preserve the dignity in death, and to preserve the mutual trust and respect between the treating physicians and patients. It facilitates the process of informed decision-making ensuring discussion, opportunity for a clear understanding in private about “do not attempt resuscitation’ (DNAR) and its implications. The ... treating physician should deliver complete information to patient/ surrogate to enable them to understand the implications of cardiopulmonary resuscitation in the context of the incurability of the disease and the almost impossible chance of meaningful survival or quality of life, and to understand about DNAR. The position paper also provides an algorithm for DNAR decision-making which would guide the physicians in making the right decisions about treatment on case to case basis. It also stresses about the importance of continuing supportive and compassionate care of the patient. A patient/surrogate information sheet clarifies the terminologies that have been used to explain in simple words how the decisions would be arrived at by the physician. <http://bit.ly/2DH0Tlg>

Noted in Media Watch 14 May 2018 (#563, p.6):

- *INDIAN JOURNAL OF CRITICAL CARE MEDICINE*, 2018;22(4):249-262. ‘**Definition of terms used in limitation of treatment and providing palliative care at the end of life: The Indian Council of Medical Research Commission report.**’ Indian hospitals, in general, lack policies on the limitation of inappropriate life-sustaining interventions at the end of life (EoL). To facilitate discussion, preparation of guidelines and framing of laws, terminologies relating to the treatment limitation, and providing palliative care at the EoL care need to be defined and brought up to date. This consensus document on terminologies and definitions of terminologies was prepared under the aegis of the Indian Council of Medical Research. **Full text (via PubMed):** <http://bit.ly/362Ft4p>

Spirituality in older men living alone near the end-of-life

NAGOYA JOURNAL OF MEDICAL SCIENCE, 2019;81(4):557-570. Older people living alone has been reported to be socially isolated and suffering from loneliness. Although spiritual care is a core element of end-of-life (EoL) care for older people, a clear-cut definition of spirituality has not been established yet. It remains unclear how spirituality is perceived by healthcare professionals and how spiritual care is delivered at the EoL. Also, most of the previous studies on perspective of older people living alone targeted women, while very few researches shed light on the experience of older men. The aim of the present study was to investigate the spirituality of older men living alone near the EoL. Five main themes emerged: 1) Worthlessness and hopelessness; 2) Autonomy and independence; 3) Comfort and gratitude; 4) Past experiences; and, 5) Well-being indicator. The authors’ findings provide important additional information that can help clinicians, nurses and care managers achieve better patient-centered care for older men living alone and enhance their dignity. **Abstract:** <http://bit.ly/35ZXdNT>

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

Noted in Media Watch 2 December 2019 (#642, p.14):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 26 November 2019 – ‘**Patient’s spirituality perspectives at the end of life: A qualitative evidence synthesis.**’ Fifty papers (42 unique datasets), incorporating data from 710 patients were included. Studies recruited from a mix of inpatient, outpatient, hospice and community settings across 12 different countries. Three overarching themes were generated: 1) The concept of spirituality; 2) Spiritual needs and distress; and, 3) Spiritual care resources. Relationships were an intrinsic component of spirituality. Meeting patients’ spiritual needs is an integral part of end-of-life (EoL) care. This work emphasises that supporting relationships should be a central focus of spiritual care for patients at the EoL. **Abstract:** <http://bit.ly/35HOUGl>

N.B. Selected articles on spirituality in the context of EoL care noted in 12 August 2019 issue of Media Watch (#626, p.9).

Surprise questions that can improve end-of-life care

NURSING OLDER PEOPLE, 2019;31(6). Healthcare professionals can help meet the needs of older people approaching the end of life by asking the right questions The National Health Service Long Term Plan pledges to introduce personalised and proactive care planning for people in their final year of life.¹ Improving communication is vital to this. **Access article at:** <http://bit.ly/2YgJxLM>

1. 'The National Health Service Long Term Plan,' January 2019. **Download/view at:** <http://bit.ly/2LkFrNf>

Religious and cultural challenges in paediatrics palliative care: A review of literature

PEDIATRIC HEMATOLOGY ONCOLOGY JOURNAL | Online – 26 November 2019 – This review provides an insight into the religious and cultural challenges when managing children end-of-life care. The thematic analysis from the study highlights the fact that cultural traditions are dynamic and cannot be generalized to all families. Conventional medicine is assumed as mechanistic and impersonal, whereby spiritual and religious needs are commonplace among Asian populations, especially among adolescents. The spiritual and psychological care for the family should also be continued after the child's death, in providing adequate social support as bereavement process may even last way after the child's passing due to the remaining guilt and unspoken frustration. Ambivalence is particularly ubiquitous among adolescents or young adults when dealing with terminal diseases. Coping strategies in families with children who are too young to understand the concept of

dying is more complicated. Spiritual coping was seen to have a better outcome of bereavement as it provides comforting belief and reassurance to the living. **Full text:** <http://bit.ly/2DyuvYb>

Extract from *Pediatric Hematology Oncology Journal* article

Traditional healers were the first choice opted by families coming from the deep-rooted cultural regions when their children experience health issues. Native Americans, in particular, were found to prefer information to be shared with the eldest community leader before a cumulative decision is made pertaining to the subsequent plan of care. Furthermore ... religious and cultural practices are a norm when dealing with terminally ill children, such as drinking of "purified" water read with Quranic verses by the Moslem patients, Shabad and Parth rituals among Sikh, or fasting in Hinduism, when dealing with health adversity of a family member.

Noted in Media Watch 28 January 2019 (#599, p.10):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 24 January 2019 – '**Pediatric palliative care in the multi-cultural context...**' Recommendations of workshop participants included phrases to navigate emotional conflict, broken trust, unfamiliar family values, and conflict. Suggested approaches to training and clinical care included the development of core competencies in communication, history taking, needs assessment, and emotional intelligence. Important opportunities for scholarship included qualitative studies exploring diverse patient – and family – experiences, quantitative studies examining health disparities, and randomized clinical trials testing interventions designed to improve community partnerships, communication, or child health outcomes. **Full text:** <http://bit.ly/2KXVTUd>



[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>

Response to suffering of the seriously ill child: A history of palliative care for children

PEDIATRICS | Online – 5 December 2019 – Most pediatric clinicians aspire to promote the physical, emotional, and developmental well-being of children, hoping to bestow a long and healthy life. Yet, some infants, children, and adolescents confront life-threatening illnesses and life-shortening conditions. Over the past 70 years, the clinician's response to the suffering of these children has evolved from veritable neglect to the development of pediatric palliative care (PPC) as a sub-specialty devoted to their care. In this article, the authors review the history of how clinicians have understood and responded to the suffering of children with serious illnesses, highlighting how an initially narrow focus on anxiety eventually transformed into a holistic, multidimensional awareness of suffering. Through this transition, and influenced by the adult hospice movement, PPC emerged as a new discipline. Becoming a discipline, however, has not been a panacea. The authors conclude by highlighting challenges remaining for the next generation of PPC professionals to address. **Abstract:** <http://bit.ly/36bf306>

Palliative care Needs Rounds in rural residential aged care: A mixed-methods study exploring experiences and perceptions of staff and general practitioners

PROGRESS IN PALLIATIVE CARE | Online – 4 December 2019 – New approaches are needed to assist residential aged care (RAC) staff increase their skills and confidence in identifying when residents are nearing the dying phase and managing symptoms. One new evidence-based approach to improve palliative and end-of-life (EoL) care in RAC is outreach Specialist Palliative Care Needs Rounds (monthly triage and risk stratification meetings – hereafter Needs Rounds); as yet untried in rural settings which may face unique enablers or challenges. Needs Rounds were introduced into two RAC facilities in the rural Snowy Monaro region of New South Wales, Australia. This study explored staff and general practitioners' experiences and perceptions of palliative and EoL care in rural RAC, and staff confidence and capability in providing such care, prior to, and after the introduction of Needs. Despite system and site-specific barriers, staff self-reported that Needs Rounds increased their capability in providing EoL care, and improved staff: 1) Awareness of EoL, reflective practice, and critical thinking; 2) EoL decision-making and planning; and, 3) Pain management. Further studies should explore running Needs Rounds via telehealth and/or utilizing a multidisciplinary approach. **Abstract:** <http://bit.ly/35XTgZY>



**Australian
National
University**

N.B. Additional articles on the provision and delivery of palliative and EoL care in rural and remote regions of Australia noted in 18 November 2019 issue of Media Watch (#640, p.14).

Medical students do not feel confident in managing palliative care as future doctors

PROGRESS IN PALLIATIVE CARE | Online – 4 December 2019 – Surprisingly, studies have shown that education in palliative care (PC) at Danish medical schools is below international standards. Generally, participants [i.e., survey respondents] reported low confidence in managing PC. Lowest confidence was found regarding conversion from oral to subcutaneous administration of medicine, whereas participants felt more confident in communication related to PC. Male respondents reported higher confidence in managing PC than females. Positive opinions on the relevance of PC education and of implementing more PC education were reported. This study showed that improvements of PC education at Danish medical schools are pivotal. **Abstract:** <http://bit.ly/2OOaaUX>

N.B. Additional articles on hospice and PC in Denmark noted in 10 June 2019 issue of Media Watch (#617, p.13).



Would this article be of interest to a colleague?

**“Triggers” for early palliative care referral in patients with cancer:
A review of urgent unplanned admissions and outcomes**

SUPPORTIVE CARE IN CANCER | Online – 2 December 2019 – Many triggers have been proposed, but are not commonly used. This study reviewed the timing of palliative care (PC) involvement for patients in a tertiary referral oncology hospital, and whether the use of a trigger tool prior to admission would have facilitated earlier referral. A total of 159 patients were identified. Forty-six percent were referred to PC prior to terminal admission. Application of 6 out of 7 trigger tools would have resulted in the majority of patients (up to 91.2%) referred to PC prior to admission. Most patients (52.2%) were referred only during their terminal admission. Patients known to PC before admission were reviewed quicker than those who were not... In this patient cohort, a palliative referral trigger tool may have proactively identified most patients prior to their terminal admission. Prospective testing of trigger tools in oncology populations is warranted. **Abstract (w. list of references):** <http://bit.ly/34GKMGP>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 2 December 2019 – ‘**Results from a survey of American Geriatrics Society members’ views on physician-assisted suicide.**’ No prior study explores the views of the American Geriatrics Society (AGS) membership on physician-assisted suicide (PAS). 1,488 randomly selected AGS members were surveyed via email. There was no consensus regarding the acceptability of PAS, with 47% supporting and 52% opposing this practice. PAS being legal in the respondent’s state, belief that respect for autonomy alone is sufficient to justify PAS, and intent to prescribe or support requests for PAS if legal in state of practice all correlated with support for PAS. There was no consensus on whether the AGS should oppose, support, or adopt a neutral stance on PAS. Most respondents believed that PAS is more complex among patients with low health literacy, low English proficiency, disability, dependency, or frailty. Most respondents supported mandatory palliative care consultation and independent assessments from two physicians. Themes identified from qualitative analysis include role of the medical profession, uncertainty of the role of professional organizations, potential unintended consequences, autonomy, and ethical and moral considerations. There was no consensus among respondents regarding the acceptability of PAS. Respondents expressed concern about vulnerable older populations and the need for safeguards when responding to requests for PAS. Ethical, legal, and policy discussions regarding PAS should consider vulnerable populations. **Abstract:** <http://bit.ly/2OJ4KdW>

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