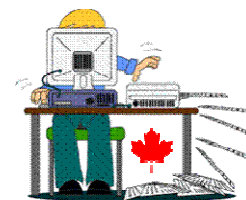


Media Watch...

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

Many palliative care services continue to adopt an unhelpful standardised approach in offering bereavement support. So, who provides support to the bereaved? Who needs support and to what extent? Importantly, who is perceived by bereaved people to have offered them support and was it helpful?

'Bereavement support: From the poor cousin of palliative care to a core asset of compassionate communities' (p.10), in *Progress in Palliative Care*.

Canada

It's not the same old story: Canada's aging population is on the rise, but we don't have the resources to match

THE GLOBE & MAIL | Online – 13 January 2020 – According to 2019 Canadian population data, 17% of our population – or 6.5 million Canadians – are older than 65. This number is growing rapidly. In comparison, children (14 years and younger) represent 16% of the population, and this number has been steadily declining. But our medical system doesn't currently reflect these significant demographic shifts. Geriatricians play an important role in specialized care, helping older adults maintain their independence, providing guidance on the care of older adults in long-term care homes and offering consultation on more complex cases of older people admitted to hospitals – and Canada only has 304 of them. According to the Canadian Medical Association, most provinces have about one geriatrician for every 100,000 older adults and three of our provinces have only one geriatrician for the entire province. Within each province, most geriatricians practise primarily in urban areas, leading to geographic inequality in the ability to access their expertise. <https://tgam.ca/30oq4K3>

From the archives

Canada needs twice as many palliative specialists

CANADIAN MEDICAL ASSOCIATION JOURNAL, 2017;189(1):E34-E35. Canada doesn't have enough palliative care (PC) doctors to give suffering patients an alternative to assisted death, the Canadian Society of Palliative Care Physicians warns in a new report.¹ The group anticipates about 62,400 Canadians will request medical assistance to die in 2017. Meeting their PC needs will require the equivalent of 170 specialists working 40 hours a week for a year – double the number currently practising in Canada. **Full text:** <http://bit.ly/36ZxHcc>

1. 'How to Improve Palliative Care In Canada,' Canadian Society of Palliative Care Physicians, November 2016. [Noted in 7 November issue of Media Watch (#486, p.2)] **Download/view at:** <http://bit.ly/2QUPoUV>

Cont.

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- BRITISH COLUMBIA | *The BC Catholic* (Vancouver) – 17 January 2020 – ‘**Hospice willing to lose \$750K rather than allow euthanasia onsite.**’ A Ladner hospice is willing to forego hundreds of thousands of dollars in government funding rather than bow to pressure from Fraser Health Authority and B.C. Health Minister Adrian Dix to provide assisted suicide on site. The Delta Hospice Society has been given until February to comply with orders from Fraser Health to offer medical aid [*sic*] in dying (MAiD) at the 10-bed Irene Thomas Hospice in Ladner. But in an interview with *The BC Catholic*, the hospice president says the organization would rather lose \$750,000 in government funding than offer lethal injections. “MAiD is completely incompatible with palliative hospice care. It’s diametrically opposed,” Angelina Ireland, said... In refusing to provide assisted suicide, the hospice is only complying with its constitution, Ireland said. “We believe that we haven’t done anything wrong ... We believe we are following on what palliative hospice care truly is.” Ireland said the hospice is so determined, it is offering to give up \$750,000 of government funding, which would ensure the hospice is under the 50% funding threshold set by the government, therefore exempting it from providing assisted suicide. Currently, the hospice receives \$1.4 million a year from the government. <http://bit.ly/2NEPAWp>

Noted in Media Watch 30 December 2019 (#646, p.1):

- BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 24 December 2019 – ‘**Here’s the deadline given to Delta Hospice.**’ The Fraser Health Authority (FHA) has given the Delta Hospice Society a deadline to agree to provide medically assisted deaths. The new board of the Society has been on a collision course with the health region after reversing a decision by the previous board to not allow medical assistance in dying (MAiD) at the Irene Thomas Hospice in Ladner. A spokesperson with the region told the *Optimist* that the FHA “reached out again to the Society to share our expectations that they comply to permit MAiD by 3 February 2020.” Health region representatives recently met with the leadership from the Delta Hospice to discuss the Society’s compliance of their contract. <http://bit.ly/2tM3AWZ>

Noted in Media Watch 23 December 2019 (#645, p.1):

- BRITISH COLUMBIA | *The Delta Optimist* (Ladner) – 18 December 2019 – ‘**Canadian palliative society supporting Delta Hospice.**’ The public and many healthcare providers have had a longstanding fear that hospice and palliative care (PC) hastens peoples’ deaths, something that will be made worse if facilities are forced to provide medical assistance in dying (MAiD). That’s what the Canadian Society of Palliative Care Physicians (CSPCP) is saying in a letter to the province’s Health Minister Adrian Dix in support of the Delta Hospice Society... A CSPCP submission to a federal special joint committee on MAiD as well as a joint statement with the Canadian Hospice Palliative Care Association note hospice and PC and MAiD substantially differ in philosophy, intent and approach.^{1,2} <http://bit.ly/2r8VuH3>
 1. ‘Presentation to Special Joint Committee on Physician-Assisted Death,’ Canadian Society of Palliative Care Physicians, July 2016. **Download/view at:** <http://bit.ly/38TNbjj>
 2. ‘Joint Statement Regarding Palliative Care and Medical Assistance in Dying,’ Canadian Hospice Palliative Care Association & Canadian Society of Palliative Care Physicians, December 2019. [Noted in 2 December 2019 issue of Media Watch (#642, p.1)]. **Download/view at:** <http://bit.ly/33mmlad>
- *THE GLOBE & MAIL* | Online – 12 January 2020 – ‘**Ottawa launches public consultations to meet court deadline to loosen rules for medically assisted death.**’ The federal government is launching public consultations to renew its assisted dying law, with an eye to tabling legislation in the spring to loosen some of the rules governing the practice across Canada. The Quebec Superior Court forced the government to amend the federal law last September by striking down a portion that limited access to terminally ill patients whose natural deaths were deemed to be “reasonably foreseeable.” Justice Minister David Lametti and Health Minister Patty Hajdu will attend round tables with experts and oversee an online consultation with Canadians on the best way to amend the law. They will also engage with opposition parties, whose support will be essential to adopting new legislation in a minority Parliament, as well as provincial and territorial governments. Ottawa is looking to address three contentious issues: cases in which mental illness is the sole reason for requesting an assisted death; cases in which patients want to make an advance, written request for assisted death before they lose the capacity to consent; and cases involving patients under the age of 18 who are deemed capable of making their own medical decisions. Four months ago, Quebec Superior Court Justice Christine Baudouin said the law was unconstitutional because it forced two Quebecers with incurable conditions ... to keep living in great pain. Justice Baudouin gave Ottawa until March to amend the law. <https://tgam.ca/2Nlq9sC>

U.S.A.

Dying in the neurosurgical ICU

THE NEW YORK TIMES | Online – 14 January 2020 – Brain death is stark and final. When the patient’s brain function has ceased, bodily death inevitably follows, no matter what we do. Continued interventions, painful as they may be, are necessarily of limited duration. We can keep a brain-dead patient’s body alive for a few days at the most before his heart stops for good. Trickier and much more common is the middle ground of a neurologically devastating injury without brain death. Here, decisions can be more difficult, and electing to continue or to withdraw treatment much more problematic. Inconsistent communication and support between medical staff members and families plays a role. A new field, neuropalliative care, seeks to focus “on outcomes important to patients and families” and “to guide and support patients and families through com-

plex choices involving immense uncertainty and intensely important outcomes of mind and body.”¹ <https://nyti.ms/3a6qvNv>

Specialist Publications

‘Grief before and after bereavement in the elderly: An approach to care’ (p.10), in *American Journal of Geriatric Psychiatry*.

‘Updates in hospital palliative care’ (p.5), in *American Journal of Hospital Medicine*.

‘Recent legislation that secured a “right-to-try” unapproved drugs: Why the “fuss” over a “fix” of what “ain’t broke”?’ (p.11), in *Wake Forest Journal of Law & Policy*.

1. ‘Neuropalliative care: Priorities to move the field forward,’ *Neurology*, 2018;91(5):217-226. **Abstract:** <http://bit.ly/2smjzuz>

Noted in Media Watch 1 April 2019 (#608, p.13):

- *NEUROLOGY* | Online – 27 March 2019 – **‘Palliative care and inpatient neurology. Where to next?’** Palliative care (PC) may be helpful at any point along an illness trajectory, may be provided by non-PC specialists (so called primary PC), and is useful for patients with non-cancer diagnoses, including neurologic illness. Although the potential value of the PC approach for patients affected by acute and chronic neurologic illness has been recognized for 20 years, there has been a spike in interest in this topic over the past 5 years, including the emergence of neuropalliative care as a defined sub-specialty. As this field grows, so does the need for empirical research to guide clinical, educational, and research efforts. **Abstract:** <http://bit.ly/2JNTiNE>



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>



Media Watch: Behind the Scenes
<http://bit.ly/2MwRRAU>

International

Government issues findings after probe into controversial St. Margaret's Hospice decision

U.K. (England) | Somerset Live (Yeovil) – 15 January 2020 – St Margaret's Hospice trustees complied with legal duties when making the decision to close its Yeovil in-patient unit, the government has found. The hospice announced in July that it was planning to drop all 12 beds at its Yeovil branch in an effort to concentrate resources on outpatient care in the area. But after an outcry of anger from fundraisers the Charity Commission launched an investigation into the controversial plans in October 2019. The government authority opened a regulatory compliance case to scrutinise the decision-making of the trustees at the hospice. After completing its investigation, the commission ... released its findings, which state "trustees complied with le-

gal duties in making the difficult decision to close Yeovil in-patient unit." <http://bit.ly/38dpZvx>

Specialist Publications

'An European Association for Palliative Care white paper on multi-disciplinary education for spiritual care in palliative care' (p.6), in *BMC Palliative Care*.

'Thematic analysis of spousal interaction patterns among Asian parents of children with chronic life-threatening illness' (p.7), in *BMJ Open*.

'Palliative care for non-cancer conditions in primary care: A time trend analysis in the U.K. (2009-2014)' (p.7), in *BMJ Supportive & Palliative Care*.

Related:

- U.K. (England) | BBC News – 13 January 2020 – **'Sue Ryder to close "unviable Nettlebed house hospice."**' The Sue Ryder charity ... said there had been a "steady decline" of patients and a survey suggested more than 70% of respondents "would prefer to die at home." The charity said it had started a consultation with employees over the plans to close its inpatient unit "after a thorough assessment of a number of factors including patient data and costs." In a statement, the charity said the number of people referred to the inpatient unit had fallen which led to the charity cutting the amount of beds in April 2019. The charity said since April 2019, an average of four people had been cared for at the hospice, which meant the service had "become financially unviable." <https://bbc.in/2FMQYli>

Noted in Media Watch 21 October 2019 (#636, p.5):

- U.K. | *The Daily Mirror* (London) – 12 October 2019 – **'U.K. in end-of-life care crisis as 100,000 people die each year without dignity.'** Campaigners say the National Health Service is battling a shortage of 3,500 nurses needed to support people dying at home. Funding problems, meanwhile, forced the closure of a string of hospices which comfort and care for the terminally ill. And around 80% of hospices which rely on charity will fall into the red next year...¹ An extra £25 million funding was announced by the Government in August – a "drop in the ocean," said Dr. Amy Proffitt [of the Association of Palliative Medicine].² The average adults hospice receives 30% of funds from health budgets and the rest through charities, donation and fundraisers, according to Hospice UK.³ <http://bit.ly/31bGvIz>
 - 'Eight in ten charitable hospices planning a deficit budget this financial year,' Hospice UK, September 2019. [Noted in 14 October 2019 issue of Media Watch (#635, p.7)] <http://bit.ly/2obgnA9>
 - '£25 million for hospices won't go far,' *British Medical Journal*, 18 September 2019. [Noted in 23 September 2019 issue of Media Watch (#632, p.8)] Full text: <http://bit.ly/2lW27cS>
 - 'U.K. hospices face funding crisis as one in three forced to cut end-of-life services,' ITV News, 7 May 2019. [Noted in 20 May 2019 issue of Media Watch (#614, p.6)] <http://bit.ly/3071bSA>

For Hong Kong's elderly to die with dignity, much better end-of-life care is needed

CHINA (Hong Kong) | *The South China Post* – 12 January 2020 – Longevity is a blessing if there is quality of life (QoL) and dignity. Hongkongers enjoy an average life expectancy of 85 years, the highest in the world according to the World Bank, better than in Japan and Sweden. But, with the proportion of chronic

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diseases rising by age group, how Hong Kong achieves active ageing and dignified death is particularly pertinent. The World Health Organisation defines palliative care (PC) as the relief from pain and the care and support of patients and their families facing life-threatening illnesses, and which includes psychological, social and spiritual support. End-of-life care (EoLC) integrates PC and social welfare services within the last years of life. Both concepts prioritise the QoL for patients and their families, putting them in conflict with Hong Kong's treatment-centric care model. This ideological mismatch, coupled with severe resource constraints in our public healthcare system and fragmented medical-social services, impede the development of palliative and EoLC services in Hong Kong. <http://bit.ly/2slrQ23>

N.B. Additional articles on EoLC in Hong Kong noted in 14 October, 9 November and 30 December 2019 issues of Media Watch (#635, p.7, #638, p.8, and #646, p.8, respectively).

Specialist Publications

Literature review

Updates in hospital palliative care

AMERICAN JOURNAL OF HOSPITAL MEDICINE, 2019;3(4). This review critiques recent palliative care literature with likelihood of impacting general hospital practice in order to help address PC needs of patients. Findings include: 1) Early PC interventions reduced healthcare costs; 2) Prognostic awareness of surrogates of patients with advanced dementia was associated with reduced burdensome interventions; 3) Care transitions, especially in the last 3 days of life, can be detrimental to caregivers' well-being and perceptions of care; 4) Haloperidol was effective for treatment of nausea and vomiting without untoward effects; 5) Antipsychotics did not improve delirium symptoms in hospitalized patients; 6) A fan directed to the face improved dyspnea; 7) Disparities in advance directive

completion disappeared when equal opportunities were given; 8) Improving communication with families of critically ill patients improved perceptions of patient-centered care; 9) Communication-priming tools improved the quality and documentation of goals of care conversations; and, 10) Discussing prognosis did not harm the patient-provider relationship. **Full text (download/view at):** <http://bit.ly/2uXRYks>

Publishing Matters

'Predatory-journal papers have little scientific impact' (p.12), in *Nature*.

Variation in the implementation of PaTz: A method to improve palliative care in general practice – a prospective observational study

BMC PALLIATIVE CARE | Online – 16 January 2020 – PaTz (an acronym for PAlliative Thuis Zorg; palliative care at home) is a method to improve palliative care (PC) in the primary care setting in The Netherlands. PaTz has three basic principles: 1) Local GPs and district nurses meet at least six times per year to identify and discuss their patients with a life-threatening illness; 2) These meetings are supervised by a specialist PC professional; 3) Groups use a PC register on which all identified patients are listed. Since the start in 2010, the number of PaTz-groups in The Netherlands has been growing consistently. Overall, this study shows that, even though the basics are the same, the structure and content of PaTz-groups can be adapted to the preferences of the group members. As healthcare providers in all settings, including primary care, generally have a high workload and are pressed for time, multidisciplinary meetings like PaTz need to provide value. Tailoring the structure and content of the meetings to their needs and wishes is likely to increase the perceived added value, thus increasing its sustainability. In addition, the apparent flexibility of PaTz-groups introduces opportunities to improve the performance of the PaTz-groups regarding palliative patient identification and advance care planning. **Full text:** <http://bit.ly/2RtboVJ>

An European Association for Palliative Care white paper on multi-disciplinary education for spiritual care in palliative care

BMC PALLIATIVE CARE | Online – 15 January 2020 – This paper outlines a Multi-disciplinary Model of Spiritual Care (SC)... It is recommended for all palliative care (PC) services if resources are available. In order to provide spiritual care (SC) in the PC context, it is recommended that staff develop the skill of self-reflection. Several practices are available to encourage this skill. Staff needs to recognise the importance of spirituality in the life of the patient, and this requires a holistic approach, with the taking of a spiritual history and screening for spiritual need. In the event of spiritual distress, it is recommended that the patient be referred to a SC specialist, that is, a trained healthcare SC worker, for personalised intervention. SC should be integrated into the patient and caregiver care plans, with initial assessment and ongoing interventions recorded clearly in the patient notes. All staff should be on guard to avoid prejudice interfering with universal SC. While it is recognised that not all PC services will currently have the resources to reach all these goals, this document is offered as an aspirational level of SC education to be offered to PC patients. **Full text:** <http://bit.ly/2Tt29Yr>



Noted in Media Watch 13 January 2020 (#648, p.4):

- *ADVANCES IN NURSING SCIENCE* | Online – 9 January 2020 – ‘**A new perspective on spiritual care: Collaborative chaplaincy and nursing practice.**’ This article explores the domains of religion, spirituality, and culture as commonly conceptualized by chaplains, as a framework for nurses to provide spiritual care interventions to patients in acute care hospitals. Using anecdotes and illustrations from palliative care practice, this article discusses the enhanced benefits to patients and families when spiritual needs are addressed, with specialty-level chaplain interventions, primary spiritual interventions provided uniquely by nurses, or interventions that require the cooperation of both professions. **Abstract:** <http://bit.ly/2NhHPVX>

N.B. Additional articles on spirituality in the context of PC care noted in 6 January 2020 issue of Media Watch (#647, p.8). Additional articles on the role of chaplaincy in PC noted in 6 May 2019 issue of Media Watch (#613, p.8).

Palliative care for patients with substance use disorder and multiple problems: A qualitative study on experiences of healthcare professionals, volunteers and experts-by-experience

BMC PALLIATIVE CARE | Online – 14 January 2020 – In general, early palliative care (PC) interventions have more beneficial effects, predominantly on quality of life, than standard care only or late PC alone. For this reason, it is worrisome that the PC phase for patients with substance use disorder (SUD) is often identified too late. This trend is recognized within the literature for the homeless people, too. Therefore, it might be useful to develop an identification tool for this patient group or to adapt existing tools, like the PALLI for patients with intellectual disability or the Vulnerability Index for homeless people. Alternatively, set point(s)-of-entry to end-of-life services could be identified, e.g., harm-reduction service or hospitalization for acute exacerbations. Furthermore, an increased attention to advance care planning for this patient group might be an option. Despite patient’s denial of disease and dying, it may, for example, be revealing to confront them by asking the surprise question in an opposite way: “would you be surprised if you died in the next 12 months?” Such a question could be the start of exploring attitudes on and acceptance of death, dying and disease for both patients, their proxies and healthcare professionals, volunteers and experts-by-experience. From this study it appeared that many elements of the World Health Organization definition of PC seem a bit too ideal or are challenged within the actual care practice for patients with SUD. **Full text:** <http://bit.ly/2tk9LlI>



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Thematic analysis of spousal interaction patterns among Asian parents of children with chronic life-threatening illness

BMJ OPEN | Online – 19 November 2019 – While previous studies on family caregivers of patients with chronic life-threatening illness have cited emotional expression and communication between spouses as the key to relationship satisfaction, this study serves as a caution to healthcare professionals who may over-emphasise the need to openly express feelings and thoughts among Asian parent-caregivers of children with chronic life-threatening illness. The authors propose that in-depth sharing of thoughts and feelings may not be the priority for Asian couples during the period of caregiving and early bereavement. Rather, it would be useful for healthcare professionals to employ a time-efficient approach such as solution-focused narrative-based counselling when working with couples for whom functional needs such as providing care to their child take precedence. A solution-focused approach to counselling would invite both spouses to reflect on “what works,” that is, the strengths within themselves that have kept them going, the pillars of support (such as their spouse) that help reduce the strain of caregiving, and facilitate both spouses to think about what they can do to achieve more desirable outcomes within the context of their family life. **Full text:** <http://bit.ly/2uQuLR2>

Mental healthcare and palliative care: Barriers

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 January 2020 – Psychological symptoms are common among palliative care (PC) patients with advanced illness, and their effect on quality of life can be as significant as physical illness. The demand to address these issues in PC is evident, yet barriers exist to adequately meet patients’ psychological needs. This article provides an overview of mental health issues encountered in PC, highlights the ways psychologists and psychiatrists care for these issues, describes current approaches to mental health services in PC, and reviews barriers and facilitators to psychology and psychiatry services in PC, along with recommendations to overcome barriers. Patients in PC can present with specific mental health concerns that may exceed PC teams’ available resources. PC teams in the U.S. typically do not include psychologists or psychiatrists, but in PC teams where psychologists and psychiatrists are core members of the treatment team, patient well-being is improved. Psychologists and psychiatrists can help meet the complex mental health needs of PC patients, reduce demands on treatment teams to meet these needs and are interested in doing so; however, barriers to providing this care exist. The focus on integrated care teams, changing attitudes about mental health, and increasing interest and training opportunities for psychologists and psychiatrists to be involved in PC, may help facilitate the integration of psychology and psychiatry into PC teams. **Abstract:** <http://bit.ly/35YIN1e>

Palliative care for non-cancer conditions in primary care: A time trend analysis in the U.K. (2009-2014)

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 13 January 2020 – While guidelines recommend palliative care (PC) in non-cancer conditions, this has not been widely implemented. The authors examined whether the recording of a PC approach and the numbers of hospital deaths for deceased patients with heart failure, dementia, chronic obstructive pulmonary disease (COPD) and cancer have changed since the U.K. End-of-Life Care Strategy was introduced. From 2009 to 2014, proportions with a primary care record of PC increased for COPD from 13.6% to 21.2%; dementia from 20.9% to 40.7%; and heart failure from 12.6% to 21.2%; but remained substantially lower than for cancer (57.6% to 61.9%). Median days before death of recording improved for COPD (145 to 224) and dementia (44 to 209); but not for heart failure (168.5 to 153) and cancer (123 to 114). Trends in hospital deaths were not consistently downward, although the proportions of patients dying in hospital were lower in the last period compared with the first. Recording of a PC approach for non-cancer conditions has increased since the introduction of the U.K. End-of-Life Care Strategy, but remains inadequate. **Abstract:** <http://bit.ly/2Rj0xO3>



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

Children's self-reports about illness-related information and family communication when a parent has a life-threatening illness

JOURNAL OF FAMILY NURSING | Online – 13 January 2020 – Children's experiences of information and family communication when a parent has a life-threatening illness have been sparsely studied, though such information is important for the child's wellbeing. The aim of this study was to explore children's reports of illness-related information and family communication when living with a parent with a life-threatening illness. Forty-eight children, aged 7 to 19 years, were recruited from four specialized palliative home care units in Stockholm, Sweden. All but one child reported that someone had told them about the parent's life-threatening illness; however, two thirds wanted more information. A quarter of the teenagers reported that they had questions about the illness that they did not dare to ask. Half of the children, aged 8 to 12, reported that they felt partially or completely unable to talk about how they felt or show their feelings to someone in the family. Interventions are needed that promote greater family communication and family-professional communication. **Abstract (w. list of references):** <http://bit.ly/2sqIM7b>

N.B. See 'Crossroads of Grief Project: Grieving or Bereaved Children: Literature Review 2015-201,' Children & Youth Grief Network of Peel Region, Ontario, Canada. Scroll down to 'Parent illness, dying and death' (p.13). **Download/view at:** <http://bit.ly/2sQ2bLy>

Top ten tips palliative care clinicians should know about caring for serious illness in pregnancy

JOURNAL OF PALLIATIVE MEDICINE | Online – 10 January 2020 – Palliative care (PC) teams are increasingly being called upon to provide care earlier and more remote from end of life. Because much of the field has grown out of hospice and geriatric care, most teams have little to no experience caring for pregnant women or their fetuses when serious or life-threatening illness strikes. This article, written by a team of oncologists (gynecologic, medical, and radiation) and PC providers, seeks to demystify the care of seriously ill pregnant women and their fetuses by exploring the diagnostic, treatment, prognostication, symptom management, and communication needs of these patients. Truly comprehensive PC extends throughout the life span, from conception to death, regardless of age. **Abstract:** <http://bit.ly/2t7Xpge>

Engaging fathers in pediatric palliative care research

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE | Online – 17 January 2020 – The purpose of this study was to identify factors that affected paternal study invitation and participation. A secondary mixed-methods evaluation design guided examination of interview and focus group data as well as field notes from a qualitative study that examined the experiences and support needs of fathers of children with a life-limiting illness. Facilitators of paternal participation in the study consisted of: fathers' desire to gain from study participation either for themselves or others, perception of the study's importance, sense of appreciation for the study's focus on fathers and an established relationship with recruiting health care providers. Barriers to study participation included: recruiting health care providers' appraisal of fathers' lack of well-being, bereaved fathers' self-reported poor coping and the inability to locate and contact fathers, particularly after a child's death. Strategies for improving the engagement of fathers into research entailed: educating recruitment personnel, designing "father-focused" studies, communicating the value of the research to recruitment personnel and potential participants, and ensuring that child health records are accurate and include fathers' contact information. **Abstract:** <http://bit.ly/2TD9THo>

Noted in Media Watch 21 January 2013 (#289, p.7):

- *INTERNATIONAL JOURNAL OF ADOLESCENT MEDICINE & HEALTH* | Online – Accessed 15 January 2013 – '**Detached, distraught or discerning? Fathers of adolescents with chronic illness.**' The authors address the challenges to the father's role as breadwinner, leader and strength-giver in the family. Three time-periods describe the obstacles fathers tackle when parenting children with chronic disease: 1) Diagnosis and short-term, characterized by distress, isolation and uncertainty; 2) The mastery period, characterized by the struggle to establish routine and by support and spirituality; and, 3) The long-term, characterized by relationship and personality change, worries and bereavement. **Abstract:** <http://bit.ly/38u4g2D>

Moral distress in the ICU: It's time to do something about it!

MINERVA ANESTESIOLOGICA | Online – 8 January 2020 – Moral distress is a major concern among healthcare professionals (HCPs). In the intensive care unit (ICU), moral distress can result from: 1) Disagreements within the ICU team regarding life-sustaining treatments; 2) Critical illnesses that result in tragic choices regarding treatment planning; 3) Circumstances that require rapid decisions and actions without adequate consideration of all morally meaningful concerns; 4) Tensions with administrators; and, 5) Legal standards that define the decisional authority that should be held by patients and families or which forms of end-of-life care are permissible. An impressive body of research literature has highlighted the prevalence of moral distress among HCPs (including ICU HCPs), health impacts of moral distress, as well as personal and contextual factors that are strong predictors of moral distress. However, there is a paucity of knowledge on effective ways to address moral distress. Yet, action is needed because many ICU HCPs are experiencing significant moral distress. This article outlines strategies that could be used to help diminish moral distress, drawing on the available literature. These strategies include: 1) Listen attentively to your colleagues' moral distress; 2) Shift the focus from moral distress to moral agency; 3) Promote ethically-attuned discussion and education (drawing on discussion models that can help reconcile diverse ethical viewpoints or disagreements); and, 4) Provide personal supports for HCPs. Research is urgently needed to further examine which strategies are most effective for addressing moral distress in ICU settings as well as other clinical contexts. **Abstract:** <http://bit.ly/3a7F03K>

N.B. Selected articles on palliative and end-of-life care in ICU noted in 13 January 2020 issue of Media Watch (#648, pp.1-2).

Palliative care ambulance team helps more patients stay at home

NURSING TIMES | Online – 17 January 2020 – A nurse-led team at North East Ambulance Service (NEAS) has helped reduce the number of distressing hospital admissions for end-of-life (EoL) patients and vastly improved information sharing, new data shows. The Macmillan Supportive Palliative and End-of-Life Service team was established in April 2018 in a bid to improve NEAS's work with people with specialist palliative care needs or in the final days, weeks and months of life. Led by Macmillan Nurse and EoL care facilitator Sarah Turnbull, it also includes band 5 Macmillan engagement officer Paul Galloway and band 3 Macmillan admin assistant Chloe Ince. The trio has worked together to raise awareness of the needs of this vulnerable group of patients across the region, train staff and ensure more people get to die at home. A key focus has been to improve the sharing of crucial information about patients' needs, wishes and care plans. Health professionals are supposed to share information about patients with a DNACPR (do not attempt cardiopulmonary resuscitation order) or emergency healthcare plan with the ambulance service via a secure email. However, a major regional audit by the team revealed many clinicians were not doing this as a matter of routine or using outdated systems. **Full text:** <http://bit.ly/2R1yjsk>

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

- *PROGRESS IN PALLIATIVE CARE* | Online – 25 November 2019 – '**Ambulance Wish: An opportunity for public health palliative care partnerships with paramedics and other community members.**' Paramedicine and, more specifically, the role of paramedics in contexts of community-based palliative and end-of-life care (EoLC) are increasingly discussed in the literature. Within a public health palliative care framework, EoLC is viewed as a shared responsibility for everyone, including the broader community. This brief commentary discusses the international Ambulance Wish movement as an opportunity for innovative partnerships between paramedics, the PC sector, and other community members. **Abstract:** <http://bit.ly/34IDyaw>

N.B. Ambulance Wish Queensland website: <http://bit.ly/35GkHap>; History of Ambulance Wish Foundation (first established in The Netherlands): <http://bit.ly/2OOSMOO>. Selected articles on the role of paramedics in palliative and EoLC noted in 18 November 2019 issue of Media Watch (#640, p.7).

Protecting the wellbeing of nurses providing end-of-life care

NURSING TIMES | Online – 13 January 2020 – Caring for people is stressful, even for health professionals. Their support needs can be neglected, especially when they are focused on providing patient-centred care. A rise in the number of people who are dying in hospitals and hospices rather than at home is increasing the emotional labour of staff, particularly nurses, who are already coping with increased National Health Service pressures. How do health professionals – who are trained to save lives and restore health – cope when tending for people who will die in their care? This article discusses issues around work-related stress in delivering high-quality patient care. It looks at what staff and organisations can do to manage stress and avoid burnout, particularly in caring for patients who are dying, including highlighting the role of the hospital chaplaincy as a resource for all staff, be they religious or secular. **Full text:** <http://bit.ly/30iaZcN>

Noted in Media Watch 16 December 2019 (#644, p.12):

- *DEATH STUDIES* | Online – 9 December 2019 – ‘**Compassion fatigue, emotional labor, and emotional display among hospice nurses.**’ The purpose of this study was to investigate relationships between compassion fatigue, emotional labor, and emotional display among hospice nurses (HN). Study participants indicated the emotional labor they utilize is primarily suppressing both positive and negative affect. Compassion fatigue was positively associated with expressing negative emotions, faking negative emotions, negative display rule perceptions and surface acting are negatively associated with suppressing negative emotions. Interventions and policies that foster greater authenticity and support emotional regulation may help reduce compassion fatigue among HN. **Abstract:** <http://bit.ly/2P5lxlv>

Bereavement support: From the poor cousin of palliative care to a core asset of compassionate communities

PROGRESS IN PALLIATIVE CARE | Online – 12 January 2020 – The negative consequences of bereavement and the disruption of social relationships put the impact of bereavement squarely into a public health perspective. Adopting and strengthening a compassionate communities approach is necessary, not only for end-of-life care for dying people but also for providing bereavement support. Many palliative care services continue to adopt an unhelpful standardised approach in offering bereavement support. So, who provides support to the bereaved? Who needs support and to what extent? Importantly, who is perceived by bereaved people to have offered them support and was it helpful? Based on reported experiences of the bereaved in a national Australian survey, the majority of this support is provided in informal and other community settings by a range of people already involved in the everyday lives of those recently bereaved. A public health approach to bereavement care is needed to support “everyday assets” in the community without over-reach from professional services. **Abstract:** <http://bit.ly/2NktLLo>

Related:

- *AMERICAN JOURNAL OF GERIATRIC PSYCHIATRY* | Online – 11 January 2020 – ‘**Grief before and after bereavement in the elderly: An approach to care.**’ Knowledge about four distinct forms of grief can aid clinicians with the conceptualization of grief, and the assessment and care of grievers. Firstly, pre-death grief is experienced by many caregivers of terminally ill patients. Secondly, acute grief arises immediately after the death of a loved one; and, thirdly, this normally evolves to a permanent state of integrated grief after a process of adaptation. Finally, failure of adaptation results in prolonged grief disorder – intense longing for the deceased or persistent preoccupation with the deceased that lasts longer than six months after the death. **Abstract:** <http://bit.ly/2TwyDk>
- *DEPRESSION & ANXIETY*, 2020;37(1):1-98. ‘**Depression & Anxiety: Special issue on bereavement and persistent grief.**’ While the loss of a loved one is an extremely common occurrence that has been recognized as one of life’s greatest stressors throughout the history of psychiatry, and most manage to cope with loss after a period of grief and adaptation, there has been a debate about when to consider grief-related issues psycho-pathology. Nonetheless, it is only in the past year that the *International Classification of Diseases-11* (ICD-11) announced plans to include a persistent grief condition, and *Diagnostic & Statistical Manual of Medical Disorders-5* (DSM-5) continues to consider diagnostic criteria for a formal condition. **Journal contents page:** <http://bit.ly/2FH92x8>

Effectiveness of a holistic capacity-building program for volunteers in community-based end-of-life care

RESEARCH ON SOCIAL PRACTICE | Online – 14 January 2020 – Despite the importance of volunteers in end-of-life care (EoLC), ways to empower their engagement therein remain unclear. The aim of this study was to examine the effectiveness of a holistic capacity-building program for volunteers in community-based EoLC. Applicants completed a capacity-building program in four steps: motivational screening, core competence training, internships, and in-service supervision. Screening involved completing a self-administered risk assessment and being interviewed by a social worker, and a questionnaire was developed to evaluate the effectiveness of training at pre-training, post-training, and 6-month follow-up. Of 171 applicants, 88 completed core competence training after screening, and 53 continued volunteering for the 6 months that followed. Their competence in EoLC, awareness of self-care, and death work competence significantly improved after training and remained intact at 6-month follow-up. **Abstract (w. list of references):** <http://bit.ly/2udpq5W>

District nurses' views on and experiences with a telemedicine educational programme in palliative care

SCANDINAVIAN JOURNAL OF CARING SCIENCES | Online – 15 January 2020 – The purpose of this study was to inform further implementation and increase knowledge in inter-professional educational telemedicine in palliative care (PC) by exploring district nurses' views and experiences. This study demonstrated that programme content was relevant to clinical practice. Participants experienced increased focus on aspects of PC, reduced professional isolation and updated and renewed self-assurance in their knowledge base. Furthermore, it illustrated that a higher level of interaction is required to address district nurses' educational needs. Empowerment of district nurses proved difficult to demonstrate as a result of considerable barriers to interaction. Nevertheless, some examples of knowledge transfer exist indicating educational telemedicine's potential for teaching PC. The role of key nurses in post-session group discussions proved a key factor in advancing knowledge dissemination, warranting increased organisational and IT support in future implementation and indeed further research. **Full text:** <http://bit.ly/2G26XvK>

Let us talk about death: Gender effects in cancer patients' preferences for end-of-life discussions

SUPPORTIVE CARE IN CANCER | Online – 18 January 2020 – The influence of gender and the strong tendency to initiate end-of-life (EoL) conversations as late as possible hinder the access to EoL conversations in time and might disadvantage males. Therefore, the authors recommend a two-step approach to EoL discussions to achieve a more gender-sensitive approach. This two-step approach might lead to a better balance between the risk of premature stressful discussions on the one hand and missing the right time point on the other: 1) An obligatory "early" talk offering basic information about the necessity of EoL conversations or advance care planning (ACP) in general, including information about the probability of (unexpected) disease-associated incapability; and, 2) Later invitations to discuss specific EoL issues or proceed ACP with a gender-sensitive approach either using open-ended, non-confronting, and non-provocative questions (e.g., "What changes can you see taking place in the future") or using starting points in medical care or organizational "facts" particularly for men. **Full text:** <http://bit.ly/3669r78>

Recent legislation that secured a "right-to-try" unapproved drugs: Why the "fuss" over a "fix" of what "ain't broke"?

WAKE FOREST JOURNAL OF LAW & POLICY | In Press – Accessed 12 January 2020 – The significance of the federal ... Right-to-Try Act of 2017 and its state counterparts is widely misunderstood. The legislation is both more and less than it may seem at first blush. This much is clear: at the federal level, it opens a new pathway, alongside the existing Federal Food & Drug Administration regulated pathway, for making promising investigational drugs available to seriously ill patients who lack meaningful alternative options ("treatment use"). The author elucidates the real import of these laws by examining them in the

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detailed historical context of how treatment use has been regulated before their advent, and how that regulation has often been challenged, unsuccessfully. He demonstrates why the promise of the new legislation is less than proponents' bold claims (life-saving and transformative). To this end, he contrasts the new and extant pathways in light of decision factors that matter to mainstream drug developers. Proponents of "right-to-try" have a broader deregulatory agenda, and their ability to have achieved a first breakthrough is the greater significance of the recent legislative campaign. **Abstract:** <http://bit.ly/2QM5jVy>

N.B. Additional articles on "right-to-try" laws noted in 28 October 2019 issue of Media Watch (#637, p.3).

[Publishing Matters](#)

Predatory-journal papers have little scientific impact

NATURE | Online – 13 January 2020 – Papers published in "predatory" journals attract little attention from scientists, and get cited much less than those in reputable publications, an analysis shows.¹ Researchers and publishers have long voiced fears that these practices could be harming research by flooding the literature with poor-quality studies. But the authors of the analysis ... say their findings suggest papers in predatory journals have "very limited readership among academics," and therefore have little effect on science. The researchers picked 250 predatory journals from the more than 10,000 titles included on a list of such publications curated by Cabells... They then selected one paper published in 2014 from each of the 250 journals. They manually checked how many times each paper had been cited in the five years since its publication. Around 60% of the papers hadn't attracted any citations at all, and 38% were cited up to 10 times. Less than 3% of the papers attracted more than 10 citations, and none got more than 32 citations... The authors also analysed a random sample of 1,000 articles published in 2014 in reputable journals... By contrast, each of those articles had an average of around 18 citations, and only 9% of the papers were not cited. **Full text:** <https://go.nature.com/35RIRhO>

1. 'How frequently are articles in predatory open access journals cited,' Björk et al, Cornell University, December 2019. **Abstract:** <http://bit.ly/2No0HTe>

[Media Watch: Editorial Practice](#)

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

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