Health & Human Services watchdog to probe enforcement of nursing home staffing standards

KAISER HEALTH NEWS | Online – 30 August 2018 – The inspector general at the Department of Health & Human Services this month launched an examination into federal oversight of skilled nursing facilities amid signs some homes aren’t meeting Medicare’s minimum staffing requirements. The review comes on the heels of a Kaiser Health News and The New York Times investigation that found nearly 1,400 nursing homes report having fewer registered nurses on duty than the Centers for Medicare & Medicaid Services (CMS) requires or failed to provide reliable staffing information to the government. The Office of Inspector General said it would examine the staffing data nursing homes submit to the government through CMS’ new system that uses payroll records. That system gives a more accurate view of staffing than the self-reported numbers facilities had provided for nearly a decade. https://goo.gl/VYdSwm


When siblings share the caregiving for an aging parent, will it be welfare or warfare?

FORBES | Online – 29 August 2018 – Caring for aging parents is a journey many of us will take in our lives. Some will plan ahead, while others will unexpectedly become caregivers and learn as they go. Many will encounter common challenges: parents who need but refuse help, a fragmented health care system, the staggering cost of care and the daunting task of somehow finding time to juggle it all. But of all the difficulties family caregivers face, one of the biggest sources of stress is trying to get on the same page with our siblings. https://goo.gl/Mr4qnc
Office of Inspector General report on hospice vulnerabilities: Recommendations receive lukewarm support from Centers for Medicare & Medicaid Services

LEXOLOGY | Online – 28 August 2018 – The Office of Inspector General (OIG) Portfolio Report is a rehash of the watchdog agency’s 2006-2016 findings on quality of care concerns and program integrity issues.1,2 The report, which garnered some critical press attention for hospices, foreshadows continued audit pressure on hospice organizations. OIG calls for the Centers for Medicare & Medicaid Services (CMS) to increase oversight activity, change hospice payment structures and conduct additional monitoring and public reporting. CMS agrees with some but not all OIG recommendations. [Download/view at: https://goo.gl/aMJQEn]


2. ‘Vulnerabilities in the Medicare Hospice Program Affect Quality Care and Program Integrity...,’ Office of Inspector General, U.S. Department of Health & Human Services, July 2018. [Noted in the 6 August 2018 issue of Media Watch (#575, pp.3-4)]

Specialist Publications


7 Questions you should ask when choosing a hospice provider

OHIO | The Enquirer (Cincinnati) – 28 August 2018 – Choosing a hospice provider is an unfamiliar experience for most people. You or your loved one may still be reeling from the decision to move from seeking a cure to deciding instead on comfort, symptom management and quality of life. Not all hospices are alike, so it’s important that you (or someone in your family) do some homework. When you’re looking at a particular hospice provider, ask yourself the following: 1) Is the hospice for-profit or not-for-profit? 2) How experienced is the hospice? 3) What is the hospice’s mission statement, and does it resonate with what you want for yourself and your loved ones? 4) Does the hospice offer dedicated Inpatient Care Centers? 5) Does the hospice offer comprehensive grief support? 6) What amenities does the hospice provide to improve the lives of patients and families? Is the hospice community-based? [Download/view at: https://goo.gl/JLQVJQ]

Nevada’s first prison hospice opens

NEVADA | This is Reno – 25 August 2018 – The Northern Nevada Correctional Center opened the first of its kind dorm-style hospice unit in the Nevada prison system to serve inmates with severe life-ending illnesses. Today, there are approximately 100 prisons across the country that acknowledge the unique long-term physical, psychological, and spiritual needs of aging inmates. Hospice programs are a part of the solution to tackle the heavy financial burden and growing medical needs of what is reported to be the fastest growing incarcerated population: those age 55 and older. Approximately 10% of inmates serve life sentences and another 11% are sentenced to serve 20 years or more. Longer and stricter sentencing lengths to help enforce public safety is one contributing factor. However, the reality is that a majority of the aging population are first-time, violent offenders who will be facing longer sentences. Inmates age two to three times faster while in prison, and an aging body with limited access to preventative health care creates its own set of challenges. [Download/view at: https://goo.gl/m9acHT]

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (last updated 1 August 2018) is available on request. Contact information at the foot of p.0. [Download/view at: https://goo.gl/YLckx6]
My patients are dying. But it’s there right to keep going.

THE WASHINGTON POST | Online – 24 August 2018 – Aggressive treatments, such as more chemotherapy, are not going to cure these two patients. Therapy aimed at controlling their symptoms will help them live their remaining days more comfortably. Meanwhile, we still struggle with one of the primary challenges of modern medicine: end-of-life (EoL) communication. Many physicians encourage early palliative care for terminally ill patients, to make the process of dying less painful, more cost-effective and patient-focused. But if the patients are not ready, instead of feeling relief, they may experience this advice as abandonment. Without first considering how patients understand their own condition, doctors risk returning to a culture of paternalistic medicine, one where physicians make decisions for the patient in the belief that they know best. Disagreements about treatments between doctors and their patients near the EoL can be devastating. So communication is vital. EoL care is not check-list medicine. It is not just about statistics or studies. Achieving true shared decisions is an interactive process that takes time and engagement. https://goo.gl/w8Tidr

International

Want to die at home? Sorry, we can’t visit this weekend, reveals staff-crisis hospital as terminally ill patients face dying in “pain and distress”

U.K. (Wales) | The Daily Mail (London) – 1 September 2018 – Terminally ill patients face dying in “pain and distress” after a hospital secretly cancelled end-of-life care this weekend. A leaked internal document reveals that Wrexham Maelor Hospital’s specialist palliative care (PC) team is unavailable for home visits because of staff shortages. It means cancer victims could face an undignified end in A&E without proper treatment or, worse, a painful death at home. Doctors and campaigners warned last night of unacceptable failures and said the situation in Wrexham, North Wales, brings into sharp focus a growing crisis across Britain. They accused the Government of ignoring a demand in 2015 for £130 million to improve PC and ensure those facing death were given comfort, support and pain relief. Wrexham Maelor was also forced to withdraw its PC team last weekend, but promised to resume the out-of-hours service next weekend. https://goo.gl/BPA43p

Charity urges ambulance trusts ensure end-of-life care plans are met

U.K. (England) | Online – 31 August 2018 – Nearly a quarter of ambulance trusts have no systems for holding advance care plans (ACPs) for patients, a charity has warned. Compassion in Dying, which helps people prepare for the end of life, said this could result in paramedics not being aware of, and therefore failing to respect, a patient’s stated preferences for medical treatment and care. The charity said it was prompted to conduct the research after receiving frequent inquiries from people concerned about whether

Specialist Publications

‘Professionals’ perceptions and current practices of integrated palliative care in chronic heart failure and chronic obstructive pulmonary disease: A qualitative study in Belgium’ (p.8), in BMC Palliative Care.

‘What determines the timing of discussions on forgoing anticancer treatment? A national survey of medical oncologists [in Japan]’ (p.13), in Supportive Care in Cancer.

‘Consensus document of the Italian Association of Medical Oncology and the Italian Society of Palliative Care on early palliative care’ (p.13), in Tumori Journal.
their ACPs would be respected in an emergency situation or when being transported between care settings. Such plans can include an advance decision, a do not attempt cardiopulmonary resuscitation form, and/or a lasting power of attorney for health and welfare. The charity said findings from a Freedom of Information request show that trusts vary significantly in their policies and practices regarding advance care planning documentation.¹ https://goo.gl/TeiEKc

¹ ‘The role of Ambulance Trusts in respecting people’s end-of-life wishes,’ Compassion in Dying, September 2018. Download/view at: https://goo.gl/Xszd7v

N.B. Additional articles on the diversity of practices and terminology concerning the implementation and documentation of do not attempt cardio-pulmonary resuscitation in the U.K. noted in the 27 August 2018 issue of Media Watch (#578, pp.12-13).

Seniors in care homes not actively looking forward to death

SWITZERLAND | Swissinfo.ch (Bern) – 30 August 2018 – Research carried out in Swiss care homes has shed light on the previously overlooked topic of seniors’ attitudes towards death.¹ The results show that over four-fifths maintain a desire to go on living. The national research project, carried out by the University Hospitals Geneva, aimed to better understand if, why, and in what form the residents of care homes in Switzerland desire to end their days. It comes in the context of ongoing debates in Switzerland about the practical and moral use of assisted suicide, as well as ever-lengthening life expectancies (at 83.3 years, Switzerland has the second-longest in the world...). “In contrast with other studies of seniors in hospital or in their homes, residents of care homes consider themselves in good health, well-supported by staff, and do not feel like a burden on their loved ones,” Dr. Eve Rubli Truchard told Swiss public television, RTS. Of the 380 care home subjects interviewed, 84% said that they wished to keep living, while the remaining 16% revealed a desire to die, but of natural causes. Just one respondent admitted to wishing to speed up the process. As for psychological attitudes towards the inevitable, just 4% said that they were neither ready for death nor accepting of it; 50% said that they were not ready, but that they could accept it. One of the key takeaways from the study ... was that the topic of death was not a taboo in the homes visited. https://goo.gl/jwCCwJ

¹ ‘Understanding the wish to die in elderly nursing home residents,’ National Research Programme, Bern, Switzerland. https://goo.gl/eXwkBC

CPR ruling if mother of eight in vegetative state stops breathing

U.K. (England) | The Evening Express (Aberdeen) – 30 August 2018 – Doctors should try to resuscitate a mother of eight who fell into a vegetative state after suffering a cardiac arrest less than two months ago, if she stops breathing, a judge has ruled after a hearing in a specialist court. Specialists caring for the woman, who is in her 60s, wanted Mr. Justice Keehan to rule that performing cardiopulmonary resuscitation (CPR) would not be in her best interests. They said CPR would be futile and unnecessarily burdensome for her. But Mr. Justice Keehan rejected an application by hospital bosses after the woman’s children raised objections and said she should be given a chance to make a recovery. He said it was too soon to make a do-not-resuscitate decision. The judge said a time might come when CPR would not be in the woman’s best interests, but that stage had not yet been reached. Mr. Justice Keehan had analysed evidence at a hearing in the Court of Protection, where judges consider issues in relation to people who lack the mental capacity to make decisions, in London. https://goo.gl/mBJ2CU

¹3 October 2018
https://goo.gl/sxz85U
Unmarried mother must receive widows’ bereavement benefits, Supreme Court rules in landmark ruling

U.K. (England) | The Independent (London) – 30 August 2018 – An unmarried mother who was denied bereavement payments after her partner died has won a landmark Supreme Court case to access widowed parent’s allowance for her bereaved children. Siobhan McLaughlin, 46, was forced to take on an evening job after being refused the benefit payments because she was not married to her partner, who died of cancer in January 2014. The ruling has been hailed as “hugely important” by campaigners, who are now calling on ministers to ensure that all children who experience the death of a parent are supported financially on the same basis as children whose parents are married. Ms. McLaughlin initially won a case after claiming unlawful discrimination based on her marital status, but that ruling was later overturned by the Court of Appeal. She said her case was never about her, but about justice for her grieving children, and accused the government of treating them as “insignificant.” https://goo.gl/UrvBtE

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE ECONOMIST | Online – 31 August 2018 – ‘After two weeks, our assisted-dying series comes to a close.’ Few topics are as universal and as specific as death. Perhaps because of this, debates over what constitutes a “good death” can become emotionally charged, free of facts and distressing. Over the past two weeks, we have tried to buck this trend. In the first week of our assisted-dying series, 14 contributors wrote thoughtful, passionate, and considered articles on why they either support or oppose the notion of assisted dying (that is, laws that permit people to choose, under some circumstances, when they can die, usually with medical assistance, as in Switzerland, the Netherlands, Belgium and Oregon in America). In the second week, eight of those who originally took part in the series responded to others, and we had one additional submission from an organisation that opposes assisted dying. Emilie Yerby, a politician in Guernsey, wrote that although her views against assisted dying did not change, she was still struck by some of the contributors that advocated for it, including an anonymous piece written by a terminally-ill patient. https://goo.gl/edzoKA

- AUSTRALIA | Royal Australian College of General Practitioners – 27 August 2018 – ‘Western Australia a step closer to voluntary assisted dying after inquiry report.’ The inquiry’s report has recommended the Western Australia state parliament pass laws for voluntary assisted dying for people experiencing grievous and irredeemable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to that person.” The year-long inquiry by the Joint Select Committee on End-of-Life Choices recommends the State Health Minister be responsible for introducing laws. The inquiry’s proposals are similar to the laws in Victoria, which became the first state [in Australia] to pass assisted dying legislation in November last year. https://goo.gl/csrTJF


N.B. The authors of the Joint Select Committee’s report point out that “over the course of the inquiry, the committee found that too many Western Australians are experiencing profound suffering as they die ... in part, due to inequitable access to palliative care (PC).” See p.55 of the report, ‘Palliative Care,’ and pp.xxxii-xxxvi for multiple recommendations on improving access to PC.

Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I’ve been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: http://goo.gl/5CHoAG
Caregiving preferences and advance care planning among older adults living with HIV

*Journal Watch*

‘Faculty applicants attempt to inflate CVs using predatory journals’ (p.14), in American Journal of Pharmaceutical Education.  

‘New international investigation tackles “fake science” and its poisonous effects’ (p.15), on the International Consortium of Investigative Journalists website.  

‘Updated editorial guidance for quality and reliability of research output’ (p.15), in Journal of Korean Medical Science.  

‘Publish peer reviews’ (p.15), in Nature.  

‘How to respond to and what to do for papers published in predatory journals’ (p.16), in Science Editing.  

‘Indian government aims to take down predatory journals’ (p.16), in The Scientist.  

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**Related**

- HIV/AIDS ADVISOR | Online – 30 August 2018 – ‘What is the role of palliative care in the current HIV treatment era?’ Although home palliative care (PC) and inpatient hospice care have been linked with improvements in pain and other symptoms, anxiety, and spiritual well-being among people with HIV, numerous barriers to such care have been noted. These include service factors such as stigma within these settings, clinician factors including conflict between disease-oriented and PC and fear of analgesia misuse, patient factors such as reluctance to address end-of-life issues, and disease factors including lack of predictable illness course. Ironically, in the early days of HIV treatment, all care was in essence PC. **Full text: [https://goo.gl/Hfc8e3](https://goo.gl/Hfc8e3)**

- THE LANCET HIV | Online – 16 July 2018 – ‘Palliative care as an essential component of the HIV care continuum.’ This review summarises the epidemiology of HIV in relation to mortality, and the symptoms and concerns of people with AIDS and those living with HIV who have either related or unrelated advanced co-morbidities. The principles and practice of palliative care (PC) are described, and the evidence for its effectiveness and cost-effectiveness appraised. The author identifies the gaps in this type of care and presents evidence for effective models of care to address these. He details the policies that prompt governments and health systems to respond to the PC needs of their population. The author concludes with evidence-based recommendations to improve the delivery of, and access to, high-quality HIV care until the EoL. **Abstract: [https://goo.gl/TeTgcY](https://goo.gl/TeTgcY)**

**N.B.** Additional articles on PC for people living with HIV noted in the 7 May 2018 issue of Media Watch (#562, p.6).
Taking societal cost into clinical consideration: U.S. physicians’ views

AJOB EMPIRICAL BIOETHICS | Online – 30 August 2018 – Recent campaigns (e.g., the American Board of Internal Medicine Foundation’s Choosing Wisely) reflect the increasing role physicians are expected to have in stewarding health care resources. The authors examined whether physicians believe they should pay attention to societal costs or refuse requests for costly interventions with little chance of patient benefit. They conducted a secondary analysis of data from a 2010 national survey of 2,016 U.S. physicians sampled from the American Medical Association Physician Masterfile. The authors also examined whether physicians’ practice and religious characteristics were associated with their responses. 47% of physicians agreed that physicians “should not consider the societal cost of medical care when caring for individual patients,” whereas 69% agreed that physicians “should refuse requests from patients or their families for costly interventions that have little chance of benefitting the patient.” Physicians in specialties that care for patients at the end of life were more supportive of refusing such costly interventions. The authors did not find consistent associations between physicians’ religiosity and their responses to these items, though those least supportive of taking into account societal cost were disproportionately from Christian affiliations. Abstract (w. link to references): https://goo.gl/HllACn

Should physicians new to a case counsel patients and their families to change course at the end of life?

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2018;20(8):E699-E707. Although new cancer therapies have changed the prognosis for some patients with advanced malignancies, the potential benefit for an individual patient remains difficult to predict. This uncertainty has impacted goals-of-care (GoC) discussions for oncology patients during critical illness. Physicians need to have transparent discussions about end-of-life care options that explore different perspectives and acknowledge uncertainty. Considering a case of a new physician’s objections to an established care plan that prioritizes comfort measures, the authors review physician practice variation, clinical momentum, and possible moral objections. They explore how to approach such conflict and discuss whether and when it is appropriate for physicians new to a case to challenge established GoC. Full text: https://goo.gl/ELn4dy

The role of hope, compassion, and uncertainty in physicians’ reluctance to initiate palliative care

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2018;20(8):E782-E786. This article addresses whether physicians’ close ties to their patients might play an unexamined role in their reluctance to initiate palliative care. In cases characterized by uncertainty, physicians’ emotional investment in their patients and patients’ families might unduly promote decisions to continue aggressive treatment rather than transition to comfort care. Continued evaluation and communication of patient status, including scheduled objective consultations, can align compassionate actions with patients’ best interests. This argument and analysis are based on a case of new onset refractory status epilepticus. Full text: https://goo.gl/bP1GL9

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

pg. 7
Professionals’ perceptions and current practices of integrated palliative care in chronic heart failure and chronic obstructive pulmonary disease: A qualitative study in Belgium

BMC PALLIATIVE CARE | Online – 24 August 2018 – The participants mentioned that the word “palliative” is a bad word that results in undesirable confrontation with both patients and their families. Given that prognosis discussions are already challenging in chronic heart failure/chronic obstructive pulmonary disease (CHF/COPD) and that the general public image of CHF/COPD does not associate these diseases with death, participants are reluctant to mention the existence of such services, even more so early in the disease trajectory. This finding is not surprising. Even in oncological wards, where palliative care (PC) is more standardized, the term “palliative” is associated with death and end-of-life and has been empirically demonstrated to adversely affect inclusion rates and early referrals. In fact, empirical studies have found that renaming PC to “supportive care” can have a positive impact on both medical staff and the patients and leads to improved inclusion and referral rates. It is not clear whether a change in the terminology will have a positive impact in CHF/COPD patients since Randomized Controlled Trials (RCTs) have thus far been restricted to oncology. Moreover, PC is inherently related to difficult concepts (e.g., prognosis discussions, advance care planning decisions) and this is independent of the name of such services. In other words, even if PC was renamed one would still need to address these difficult issues. [In addition] analysis clearly shows that there is a lack of bereavement support. Conversations that aim to resolve questions with family members are not available and psychologists and spiritual caregivers are very rarely available. The low level of bereavement support is a recurrent finding that can even be traced in guidelines/pathways for PC in CHF/COPD. Full text: https://goo.gl/atWUNP

Hospice use and palliative care for patients with heart failure: Never say never in medicine, but it is never too early to start the conversation

JAMA ONCOLOGY | Online – 29 August 2018 – Hospice is both a benefit and a philosophy of care to maximize the quality of life for patients whose prognosis seems less than 6 months. An interdisciplinary team, including physicians, nurses, social workers, and spiritual/bereavement counselors, provides expert medical care, symptom management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s family as well. One of its goals is to move the end-of-life care from acute care hospitals to the home. In the U.S., the Medicare Hospice Benefit pays for approximately 80% of all hospice care. Medicare Hospice Benefit pays for covered services using a per diem capitated arrangement in 1 of 4 levels of care, Routine Home Care, Respite Care, General Inpatient Care, and Continuous Home Care. Routine Home Care is the most common level of hospice care (98%) and this is provided at “home,” which includes private residence or nursing facility. When care at home is difficult owing to acute symptom management or impending death, acute inpatient care can be provided as General Inpatient Care level (1.5%) in a Medicare-contracted hospital or hospice inpatient facility. Abstract: https://goo.gl/PVsKeU

Evaluation of interprofessional health care team communication simulation in geriatric palliative care

GERONTOLOGY & GERIATRICS EDUCATION | Online – 30 August 2018 – In health care, interprofessional communication is critical to team collaboration and patient and family caregiver outcomes. Studies suggest that acquiring skills to work on health care teams and communicate with team members should occur during the early stage of professional education. The Interprofessional Education Collaborative competency-based framework was used to inform the training. An evaluation examined attitudes toward
health care teams, self-efficacy in communication skills, interprofessional collaboration, and participant satisfaction with the training experience. One hundred and eleven participants completed pre- and post-training surveys. Overall, a majority of participants (97.3%) were satisfied with the training and reported more positive attitudes toward health care teams and greater self-efficacy in team communication skills. Participants had higher collaboration scores compared to observer learners. Abstract (w. link to references): https://goo.gl/bzKbqv

Encountering offenders in community palliative care settings: Challenges for care provision

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2018;24(8):368-375. There is very little research into the way that offender management strategies impinge on the practices and decision-making of palliative care personnel in community settings. The authors discuss one part of a larger multidisciplinary study on bereavement, loss and grief in the criminal justice system. There were situations where the participants were able to identify that patients were under the jurisdiction of the criminal justice system or had relatives in custody. Three themes emerged that highlighted distinctive aspects of providing care to this patient group: 1) Patients under prison, probation or police supervision altered the dynamics of care provision; 2) Prisoners were restricted from supporting or contacting their dying relatives in the community; and, 3) Participants (professionals) were obstructed from supporting patients at home because of criminal or anti-social behaviour by relatives of the dying. Abstract (w. link to references): https://goo.gl/2sUXPF

Related

- DIMENSIONS OF CRITICAL CARE NURSING, 2018;37(5):251-258. ‘Critical care nurses’ qualitative reports of experiences with family behaviors as obstacles in end-of-life care.’ Sixty-seven end of life (EoL) obstacle experiences surrounding issues with families’ behavior were analyzed for this study. Experiences were categorized into 8 themes. Top 3 common obstacle experiences included families in denial, families going against patient wishes and advanced directives, and families directing care that negatively impacted patients. Abstracts: https://goo.gl/MzJdTa

Prepared for end-of-life care: A concept analysis

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2018;24(8):399-410. Recent international documents have highlighted the importance of preparing the nursing workforce for end-of-life care (EoLC). However, these documents do not make clear what prepared in the context of EoLC actually means. Searching the literature failed to retrieve any papers defining prepared in this context. From the author’s analysis many attributes and antecedents were synthesised. These include that a prepared nurse would be confident to: assess the dying patient, communicate with empathy, identify and manage symptoms, recognise and deal with death and dying, understand the holistic elements of dying, be comfortable with the effects of loss and bereavement on patients and self, and be self-competent. From this analysis, a clearer idea of what is needed to prepare nurses for EoLC is offered and suggestions for future research are made. Abstract (w. link to references): https://goo.gl/xnmvJG

Noted in Media Watch 11 June 2018 (#567, p.11):

- JOURNAL OF PSYCHOSOCIAL ONCOLOGY | Online – 4 June 2018 – ‘Cancer patient perspectives regarding preparedness for end-of-life care: A qualitative study.’ Despite growing interest in the concept of “preparedness,” however, there is insufficient information about what cancer patients actually need to feel prepared. Six overarching themes emerged, including readiness to manage concerns about: 1) EoL planning (e.g., goals of care, location of care); 2) Interactions with healthcare providers (e.g., communication, symptom control); 3) Interactions with family/friends (e.g., perceived burden, support); 4) Emotional well-being (e.g., existential distress, fulfillment); 5) Spiritual well-being (e.g., spiritual comfort, congregational support); and, 6) Financial well-being (e.g., medical expenses, estate planning). Abstract: https://goo.gl/XbDuTx

Cont.
To understand community perspectives of end-of-life preparedness, the authors undertook a multi-method study exploring the experiences of 25 community members and 10 stakeholders engaged in end-of-life (EoL) planning. In addition, card sorting activities and focused discussions with 97 older adults were undertaken to highlight perspectives and needs. Overall, the participants perceived many benefits to being EoL prepared, however, few community members had engaged in formal planning. Key barriers include concerns about the accessibility and accuracy of information, discomfort when engaging in EoL conversations, and perceptions about the cost associated with engaging in formal legal or financial preparations. **Abstract:** [https://goo.gl/kmRWWt](https://goo.gl/kmRWWt)

Disturbing and distressing: A mixed methods study on the psychological impact of end-of-life care on junior doctors

The Irish Medical Council has identified gaps in knowledge and communications skills of new-entrant doctors in legal, ethical and practical aspects of end-of-life (EoL) care. A questionnaire was distributed to junior doctors to determine the frequency with which the participants had managed a patient at EoL. An abbreviated Post-traumatic Stress Disorder (PTSD) Checklist-Civilian version was used to evaluate psychological distress. Critical incident technique interviews explored the challenges of caring for patients at EoL. 110 junior doctors in two teaching hospitals in Ireland completed the questionnaire: 39 (35.5%) interns and 71 (64.5%) senior house officers. In addition, interviews were carried out with interns, senior house officers and registrars. The majority (81.8%) had pronounced a death with 39.4% of senior house officers doing so more than 10 times. Three quarters (75.5%) had discussed EoL with a patient’s family. Of the 110 respondents that completed the PTSD checklist, 11.8% screened positively for PTSD. Challenges identified at interview included lack of knowledge and preparedness, difficulty communicating with family members, a lack of support and a feeling of failure. **Abstract (inc. list of references):** [https://goo.gl/eXkkhn](https://goo.gl/eXkkhn)


A model to improve hospital-based palliative care: The Palliative Care Redistribution Integrated System Model

Many hospitalized patients have unmet palliative care (PC) needs that are exacerbated by gaps in the PC subspecialty workforce. Training frontline physicians, including hospitalists, to provide primary PC has been proposed as one solution to this problem. However, improving PC access requires more than development of the physician workforce. System-level change and interdisciplinary approaches are also needed. Using task shifting as a guiding principle, the authors propose a new workforce framework (the Palliative care Redistribution Integrated System Model, or PRISM), which utilizes physician and non-physician providers and resources to their maximum potential. The authors highlight the central role of hospitalists in this model and provide examples of innovations in screening, workflow, quality, and benchmarking to enable hospitalists to be purveyors of quality PC. **Abstract:** [https://goo.gl/HC8rx6](https://goo.gl/HC8rx6)

Improving value of care for older adults with advanced medical illness and functional decline: Cost analyses of a home-based palliative care program

This retrospective cohort study involved 50 participants enrolled in a palliative care (PC) homebound program and 95 propensity-matched control patients at Mayo Clinic in Rochester, Minnesota, between 1 September 2012 and 31 March 2013. Total Medicare reimbursement was compared in the year before enrollment with the year after enrollment for participants and controls. No significant differences were observed in demographic characteristics or prognostic indices between the 2 groups. Total Medicare reimbursement per program
Participant the year before program enrollment was $16,429 compared with $14,427 per control patient, resulting in $2,004 higher charges per program patient. In 12 months following program enrollment, mean annual payment was $5,783 per patient among participants and $22,031 per patient among the matched controls. In the second year, the intervention group had a decrease of $10,646 per patient; the control group had an increase of $7,604 per patient. The difference in differences between the participant group and control group was statistically significant and favored the PC home-bound program enrollees by $18,251. Abstract: https://goo.gl/b5S3aL

Related

- JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 29 August 2018 – ‘Overcoming reluctance to accept home-based support from an older adult perspective.’ [In this study] reluctance to accept home-based support was associated with concerns over inability to complete tasks, perceptions of being burdensome to others, lack of trust in others, and lack of control. To overcome these concerns, some participants reframed the concept of independence to be “interdependence,” with people continually depending on each other throughout their lives. Subjects noted that, even if one becomes more limited over time, the recognition that one is still contributing something meaningful to society is important to overcoming refusal of home assistance. Abstract: https://goo.gl/7ht7YW

Developing the Comfort Care Case: An end-of-life resource for pediatric patients, their families, and health professionals

JOURNAL OF PALLIATIVE CARE | Online – 31 August 2018 – Caring for a child in hospital who is approaching death, in the terminal phase, requires a focus on caring for the physical, emotional, and spiritual needs of the child and family. Health professionals caring for these children and families may need to shift their focus from a treatment-focused approach aimed at cure or maintaining life to a comfort-focused approach. The Comfort Care Case (CCC) is a collection of resources designed for use in hospital to ease suffering and facilitate comfort within a pediatric end-of-life (EoL) context. The resources are intended to support the child, the family, and the health professionals involved in EoL care. This article describes the development, implementation, and education associated with the CCC in a tertiary pediatric hospital. Abstract: https://goo.gl/NfU5mo

When doctors unlearn English

JOURNAL OF PALLIATIVE CARE | Online – 24 August 2018 – Doctor-patient communication is a quintessential part of medical care. Yet, several factors challenge its effectiveness. The author, a third year pediatrics resident, explores the ways medical education creates distance between doctors’ and patients’ ability to achieve mutual understanding in the clinical setting and how she tries to overcome this barrier. Abstract: https://goo.gl/Rzx2wi

“Same same or different?” A review of reviews of person-centered and patient-centered care

PATIENT EDUCATION & COUNSELING | Online – 26 August 2018 – The authors’ analysis resulted in nine themes present in person-centered as well as in patient-centered care: 1) Empathy; 2) Respect; 3) Engagement; 4) Relationship; 5) Communication; 6) Shared decision-making; 7) Holistic focus; 8) Individualized focus; and, 9) Coordinated care. The analysis also revealed that the goal of person-centered care is a meaningful life while the goal of patient-centered care is a functional life. While there are a number of similarities between the two concepts, the goals for person-centered and patient-centered care differ. The similarities are at the surface and there are important differences when the concepts are regarded in light of their different goals. Clarification of the concepts may assist practitioners to develop the relevant aspects of care. Person-centered care broadens and extends the perspective of patient-centered care by considering the whole life of the patient. Abstract: https://goo.gl/H6FKYb
Culturally safe end-of-life care for First Nations persons living on reserve

RURAL & REMOTE HEALTH | Online – 27 August 2018 – First Nations persons in Canada are culturally diverse; however, they share a similar history of colonization, assimilation and transgenerational effects from the residential school system. These historical structures and the ongoing systemic cultural insensitivity that is found in the healthcare system contribute to First Nations persons’ overall poor health status. These factors are believed to significantly contribute to the disproportionately higher rates of chronic health issues, and the lower socio-economic and political status that First Nations people living on reserve tend to have in comparison to non-First Nations Canadians. Issues of alienation and distrust of government-aligned services are a reality that contributes to First Nations people being less likely to seek out healthcare services within the formal structures that are perceived by many to embody characteristics of a larger colonialistic, oppressive system. Often, the situation is compounded for First Nations peoples as a result of living on reserve in rural and isolated locations with poor access to culturally appropriate mainstream health care, and, for some, limited access to traditional healers. Taken together, the significant lack of resources, coupled with the distrust and reluctance to seek medical attention arising out of negative encounters with a historically culturally insensitive healthcare system, contribute to delayed treatment and an increased likelihood of more advanced disease before treatment is sought. The prevalence of terminal illnesses is increasing for both First Nations and non-First Nations Canadians, and end-of-life care services will inevitably increase with this current trend. Full text: https://goo.gl/a3Enr1

Noted in Media Watch 14 May 2018 (#563, p.10):

- RURAL & REMOTE HEALTH | Online – 28 April 2018 – ‘Wiisokotaatiwin: Development and evaluation of a community-based palliative care program in Naotkamegwanning First Nation.’ This article provides a First Nations specific model for a palliative care (PC) program that overcomes jurisdictional issues at the local level, and a methodology for developing and evaluating community-based PC programs in rural First Nations communities. The authors demonstrate how local, federal and provincial healthcare providers and organizations collaborated to build capacity, fund and deliver community-based PC. The described process of developing the program has applicability in other First Nations (Indigenous) communities and for healthcare decision makers. Full text: https://goo.gl/ZGTWrm

N.B. Additional articles on PC for Canada’s First Nations peoples noted in this issue of Media Watch.
Ethical considerations about changing parental attitude towards end-of-life care in twins with lethal disease  

*SUDAN JOURNAL OF PAEDIATRICS*, 2018;18(1):76-82. Advances in critical care and technology capabilities may lead to new ethical encounters in paediatrics, especially in the paediatric intensive care unit (PICU). As each patient has unique psychosocial and clinical condition interactions, paediatricians and healthcare providers must develop and adopt a suitable approach for ethical decision-making in the PICU. The healthcare provider needs to balance the four ethical domains of autonomy, beneficence, non-maleficence and justice, and apply these principles to clinical decision-making. One chief factor for ethical decision-making is to have a patient-centered and family-oriented management that is respectful of cultural background. Healthcare providers also need to observe professional ethical conduct and the applicable national laws. Applying these ethical guidelines in paediatric care ensures a more holistic approach to care, whether in the paediatric wards or the highly technical environment of the PICU. The authors describe two situations in which the parents of twins with a confirmed lethal disease changed their attitude towards end-of-life from full support to “do not resuscitate” and palliative care, after experiencing the palliative care of the first twin, rather than the futile effect of cardiopulmonary resuscitation in the other twin.

Full text: [https://goo.gl/ZASr3u](https://goo.gl/ZASr3u)

What determines the timing of discussions on forgoing anticancer treatment? A national survey of medical oncologists  

*SUPPORTIVE CARE IN CANCER* | Online – 25 August 2018 – End-of-life discussions (EOLd), including the option of forgoing anticancer treatment, infrequently occur until treatment options have been exhausted for advanced cancer patients. In this nationwide survey of 864 medical oncologists, the authors asked about physicians’ attitudes toward the timing of discussing the option of forgoing anticancer treatment for a simulated patient with newly diagnosed metastatic cancer, physicians’ experience of EOLd, perceptions of a good death, and beliefs. Among 490 physicians, 167 (35%) would discuss the option of forgoing anticancer treatment “now (at the diagnosis).” Physicians’ attitudes toward discussing the option “now” were significantly correlated with a greater physician-perceived importance of life completion and dying in a preferred place for a good death, and not perceiving EOLd as being severely distressing for patients/families. Reflection by oncologists on their own perception regarding a good death and beliefs about EOLd may help oncologists individualize the timing of discussing the option of forgoing anticancer treatment. Abstract (inc. list of references): [https://goo.gl/3CvCoV](https://goo.gl/3CvCoV)

Noted in Media Watch 30 July 2018 (#574, p.16):

- SUPPORTIVE CARE IN CANCER | Online – 28 July 2018 – “Family caregiver descriptions of stopping chemotherapy and end-of-life transitions.” The authors identify three patterns of transitions characterizing the shift away from active cancer treatment: 1) “We pretty much knew,” characterized by explicit discussions about end-of-life (EoL) care, seemingly shared understanding about prognosis and seamless transitions from disease-oriented treatment to comfort-oriented care; 2) “Beating the odds,” characterized by explicit discussions about disease-directed treatment and EoL care options, but no shared understanding about prognosis and often chaotic transitions to EoL care; and, 3) “Left to die,” characterized by no recall of EoL discussions with transitions to EoL occurring in crisis. Abstract (inc. list of references): [https://goo.gl/EPZp83](https://goo.gl/EPZp83)

Consensus document of the Italian Association of Medical Oncology and the Italian Society of Palliative Care on early palliative care  

*TUMORI JOURNAL* | Online – 29 August 2018 – A consensus document on early palliative care (PC) was produced by a committed Working Group of the Italian Society of Medical Oncology and the Italian Society of Palliative Care to improve the early integration of PC in medical oncology and to stimulate and

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guide the choices of those who daily face the problems of advanced stage cancer patients. The simultaneous administration of antineoplastic treatments and early PC was shown to be beneficial in metastatic cancer pathway outcomes. Patients who could benefit from early PC are those with an advanced cancer at presentation, a compromised performance status for cancer, and/or morbidities, and who are too frail to receive treatment. According to the Bruera practice models, in which the combination of cancer management with early PC can be offered, three groups of patients needing simultaneous care were identified and three different models of the delivery of PC were proposed.¹ In patients with good prognosis and low need of simultaneous care, the solo practice model and the request for consultations were suggested, while in patients with poor prognosis disease with high need of simultaneous care and in conditions with high need of simultaneous care, regardless of cancer prognosis, the integrated care approach should be offered. PC consultation services are seldom accessible in the majority of Italian hospitals; thus the application of various practice models depends on available resources, and a shared care model with the structures of PC operating in the area is often required. Full text: https://goo.gl/Ko6KBA

1. 'Integrating supportive and palliative care in the trajectory of cancer: Establishing goals and models of care,' Journal of Clinical Oncology, 2010;28(9):4013-4017. Full text: https://goo.gl/YqVtdy

Noted in Media Watch 1 June 2015 (#412, p.12):

- RECENTI PROGRESSI IN MEDICINA, 2015;106(5):201-202. ‘Early palliative care.’ Several randomized controlled trials have demonstrated the efficacy of early palliative care (PC), in particular in cancer patients and, more recently, also in patients with other advanced life-threatening illnesses. Results have been consistent in showing that early PC improves quality of life without negatively affecting survival compared with more aggressive treatment options. Full text: https://goo.gl/OrCyCi

N.B. Italian language article.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- CANADIAN JOURNAL OF PUBLIC HEALTH | Online – 27 August 2018 – ‘Quebec physicians’ perspectives on medical aid in dying for incompetent patients with dementia.’ 136 physicians [who responded to a postal survey] favoured continuous deep sedation (CDS) over medical assistance in dying (MAiD) for relieving suffering in a cancer vignette. In advanced dementia, 45% of physicians supported giving the patient access to MAiD with a written request and 14% without such request. At the terminal stage of dementia, these proportions increased to 71% and 43%, respectively, reaching 79% and 52% among family physicians. Support for CDS in terminal dementia was lower than in end-stage cancer and equal to MAiD with a written request. Many Quebec physicians support extending MAiD to incompetent patients with dementia to relieve suffering at the terminal stage. This finding will inform current deliberations as to whether MAiD should be extended to these patients. Abstract (inc. list of references): https://goo.gl/GF2Z4E

Journal Watch

Faculty applicants attempt to inflate CVs using predatory journals

AMERICAN JOURNAL OF PHARMACEUTICAL EDUCATION | Online – Accessed 30 August 2018 – Recently, scientific publishing has experienced an expansion of journals and publishers whose primary goal is profit and whose peer review process is virtually non-existent. These “predatory” or “opportunistic” journals pose a threat to the credibility and integrity of legitimate scientific literature, and quality science could be called into question. Unfortunately, many scientists choose to publish in these journals and/or serve on their editorial boards, either due to ease of rapid publication or naivety. The authors highlight the
extensive use of predatory publications or editorial board involvement by applicants applying for a faculty position in the pharmaceutical sciences department at the Bill Gatton College of Pharmacy at East Tennessee State University. They caution search committees at other pharmacy schools to thoroughly examine applicant curricula vitae for predatory publishing. Abstract: https://goo.gl/Ht1Yos

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

**New international investigation tackles “fake science” and its poisonous effects**

INTERNATIONAL CONSORTIUM OF INVESTIGATIVE JOURNALISTS | Online – 20 July 2018 – Hundreds of thousands of scientists worldwide have published studies in self-described scientific journals that don’t provide traditional checks for accuracy and quality, according to a new journalistic investigation.¹ Dozens of reporters from media outlets in Europe, Asia and the U.S. have analysed 175,000 scientific articles published by five of the world’s largest pseudo-scientific platforms including India-based Omics Publishing Group and the Turkey-based World Academy of Science, Engineering & Technology, or Waset. In addition to failing to perform peer or editorial committee reviews of articles, the companies charge to publish articles, accept papers by employees of pharmaceutical and other companies as well as by climate-change skeptics promoting questionable theories. Some of those publishers send targeted emails to scientists who are under pressure to publish as many articles as possible in order to obtain promotions and improve their curriculum, according to the findings by Norddeutscher Rundfunk, WDR and Süddeutsche Zeitung. In addition to the German outlets, a group of more than a dozen media organizations including The New Yorker, Le Monde, The Indian Express and the Korean outlet Newstapa took part in the investigation. https://goo.gl/rY2Xsp

1. ‘More than 5,000 German scientists have published papers in pseudo-scientific journals,’ Norddeutscher Rundfunk, 19 July 2018. [Noted in the 20 August 2018 issue of Media Watch (#577, p.18)] https://goo.gl/teubyb

**Updated editorial guidance for quality and reliability of research output**

JOURNAL OF KOREAN MEDICAL SCIENCE, 2018;33(35):E247. The authors overview some of the recent editorial policy statements of global editorial associations and reflects on the role of the regional counterparts in advancing scholarly publishing. One of the globally promoted documents is the recommendations of the International Committee of Medical Journal Editors.¹ Its latest versions contain statements on proper research reporting, reviewing, editing, and publishing. Points on ethical target journals and “predatory” sources are also available. This year, in a move to update its editorial policy, the Committee on Publication Ethics released the Core Practices, comprehensively reflecting on the major issues in publication ethics.² Updated joint statements of medical writers associations are also available to implement transparent policy on contributorship in sponsor-supported research projects and related reports. Several suggestions are put forward to improve global editorial statements on online profiling, crediting, and referencing. Full text: https://goo.gl/vfQnyx

1. ‘Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals,’ International Committee of Medical Journal Editors, 2017. Download/view at: https://goo.gl/IDg1uD

2. ‘Core Practices,’ Committee on Publication Ethics. Download/view at: https://goo.gl/6RayRY

**Publish peer reviews**

NATURE | Online – 29 August 2018 – Less than 3% of scientific journals allow reviews to be published. In a 2016 survey, 59% of 3,062 respondents were in favour of open reports.¹ The vast majority of scientists think that peer review is essential for vetting research papers. The process gives authors constructive feedback, offers editors insight, and assures readers of the trustworthiness of research. Generally, how-
ever, only editors, authors and (sometimes) reviewers see referee reports. That enables several forms of abuse: referees might be superficial, rude or biased; authors might respond inadequately to reasonable criticism; editors might not hold authors or reviewers to account; and, predatory publishers will charge fees without providing quality review. Many benefits would accrue from publishing peer reviews—The scientific community would learn from reviewers’ and editors’ insights. Social scientists could collect data (for example, on biases among reviewers or the efficiency of error identification by reviewers) that might improve the process. Early-career researchers could learn by example. And, the public would not be asked to place faith in hidden assessments. Full text: https://goo.gl/9n8RWL

1. ‘Survey on open peer review: Attitudes and experience amongst editors, authors and reviewers,’ Plos One, published online 18 December 2017 (#543, p.21). [Noted in the 18 December 2017 issue of Media Watch (#543, p.21)] Full text: https://goo.gl/Aoj2yg

How to respond to and what to do for papers published in predatory journals

SCIENCE EDITING, 2018;5(2):146-149. Predatory publishing, a destructive phenomenon that has been highlighted and discussed since 2011, is the consequence of the gold (author-pays) open access publishing model. Predatory journals are money-making stations characterized by charging publication fees and an absence of “true” peer review. These journals and publishers have grown to a very large number in recent years. The general assumption is that the most common victims of such journals are young, naive, early career researchers, especially from developing countries, but this may not always be the case. Recent evidences suggest that predatory publishing is a global phenomenon affecting authors from both developing and developed countries, and even experienced authors get duped. How can we deal with these publishers and how can authors avoid getting duped by them? The author presents a few incidents to build on for answering these questions. Full text: https://goo.gl/QjxDqM

Indian government aims to take down predatory journals

THE SCIENTIST | Online – 29 August 2018 — Universities in India had until 30 August to present a “white list” of recognized journals to the University Grants Commission (UGC), a government body that provides funding and maintains higher-education standards in the country. In previously submitted recommendations, universities have included predatory journals, publishers that charge high fees for low-quality or no peer review. “We will end this menace of predatory journals,” Prakash Javadekar, the minister of Human Resources Development for India, said during a parliamentary session last month, according to Nature.¹ Not only are several publishers of predatory journals based in India, but also a large number of the studies reported in these outlets are credited to Indian academics, reports Nature. However, researchers claim that the government’s overhaul of the academic assessment system in 2010 led to this state of affairs. The UGC’s new format emphasized the number of publications a scientist authored and forced universities to use that productivity as a determining factor during hires and promotions. In January 2017, the UGC collated a white list of journals with the help of universities, but were initially unaware of the inclusion of several predatory publishers. Then in May 2018, the UGC deleted 4,305 journals from this list. https://goo.gl/wK4PKM


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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CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: [https://goo.gl/BLgxy2](https://goo.gl/BLgxy2)

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

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

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