Canada

A Palliative Approach to Care in the Last 12 Months of Life

ONTARIO | Registered Nurses’ Association of Ontario – Accessed 6 March 2020 – The Association’s best practice guidelines are systematically developed, evidence-based documents that include recommendations on specific clinical, healthy work environment and health system topics. They are intended for nurses and members of the interprofessional health team in direct care positions, and for educators, administrators and executives, policymakers, researchers, and persons and families with lived experience. The guidelines promote consistency and excellence in clinical care, administrative practices, policies, and education, with the aim of achieving optimal health outcomes for people, communities and the health system as a whole. Their purpose is to provide evidence-based recommendations to nurses and the interprofessional health team who support adults (18 years and older) experiencing the last 12 months of a progressive life-limiting illness, their families and their caregivers. The goals of the recommendations are to: 1) Improve delivery of psychosocial, spiritual and culturally safe care; 2) Enhance coordination of care; and, 3) Facilitate supportive work environments. Download/view at: http://bit.ly/2TJxTqL

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | CTV News (Montreal) – 2 March 2020 – ‘Quebec court gives Ottawa four more months to amend assisted-dying law.’ A Quebec court has given the federal government more time to amend its assisted-dying legislation. Ottawa was facing a 11 March deadline imposed last September by Quebec Superior Court Justice Christine Baudouin when she ruled it is unconstitutional to limit medically assisted death to those whose natural death is “reasonably foreseeable.” Justice Minister David Lametti filed a motion 17 February requesting a four-month extension, acknowledging the government would not be able to meet the deadline, and Baudouin agreed in a ruling today. She has extended the deadline to 11 July, but she makes a provision for those who had been hoping to access medically assisted death as of 11 March. http://bit.ly/3cCOxC
Doctors may feel “moral distress” when surrogates make decisions

REUTERS | Online – 5 March 2020 – When patients cannot make their own decisions about life-prolonging care, many doctors feel “moral distress” acting on the choices of surrogates like family members, a small survey suggests. Doctors most often felt ethical strain when the patient was older or the surrogate wanted more life-sustaining treatment than the doctor felt appropriate, researchers report... “Moral distress, especially when it goes unaddressed, is associated with physician burnout,” said coauthor Lucia Wocial, a nurse ethicist at Indiana University Health in Indianapolis. “The more we learn about what contributes to physician moral distress, the more we can intervene to help them to overcome barriers to doing what they feel is the right thing to do,” she told Reuters Health. Wocial and colleagues analyzed survey responses from 154 doctors with patients in intensive care units who lacked the capacity to make decisions. Surrogate decision-makers for 362 patients also took part in the survey. Doctors reported experiencing moral distress when caring for 152 of the patients, or about 42%. In general, disagreements between the doctor and surrogate about the plan of care didn’t cause much distress. Instead, doctors were more likely to feel moral conflict when facing a decision about life-sustaining treatment, especially when the doctor preferred a comfort-focused or hospice-focused plan. https://nyti.ms/2TvYWXQ

### Specialist Publications

- “Impact of length of hospice on spending and utilization among Medicare beneficiaries with lung cancer” (p.6), in American Journal of Hospice & Palliative Medicine.
- “Online training is great but human interaction is better”: Training preferences of Veterans Affairs interdisciplinary palliative care consult teams’ (p.6), in American Journal of Hospice & Palliative Medicine.


Noted in Media Watch 3 February 2020 (#651, p.9):

- **JOURNAL OF PAIN & SYMPTOM MANAGEMENT** | Online – 31 January 2020 – “‘Please keep mom alive one more day.’ Clashing directives of a dying patient and her surrogate.’ Medical care providers are legally and ethically bound to respect their patient’s wishes. As patients lose decision-making capacity at end of life, families or surrogates, who are confronted with grief, fear, self-doubt, and/or uncertainty, may ask physicians to provide treatment which contradicts the patients’ previously-stated wishes. The authors discuss the legal and ethical issues surrounding such requests, and provide guidance for clinicians to ethically and compassionately respond – without compromising their professional and moral obligations to their patients. Abstract (w. link to references): http://bit.ly/2UJ35tW

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Closing the Gap Between Knowledge & Technology

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http://bit.ly/2ThijkC

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pg. 2
Recovering the financial costs of caregiving

FORBES | Online – 4 March 2020 – According to a Transamerica Institute survey,¹ caregivers spend a median amount of $150 per month out-of-pocket to cover expenses for the care recipient; 75% of caregivers receive no financial assistance or payment for their caregiving duties; 22% of primary caregivers say their financial situation has worsened since becoming a caregiver; and, 18% of caregivers have taken a loan, hardship withdrawal and/or early withdrawal from their retirement accounts as a result of becoming a caregiver. Perhaps the most startling statistic is this one: 69% of caregivers say they gave little or no consideration into their own financial situation when deciding to become a caregiver. http://bit.ly/39tuItM


More screening for loneliness needed in vulnerable end-of-life stage, clinical experts stress

MCKNIGHT’S LONG TERM CARE NEWS | Online – 4 March 2020 – Clinicians must do more to screen for and intervene in cases of loneliness among older adults at the end-of-life (EoL) – not only during the dying period, say investigators from the University of Michigan.¹ Lonely older adults are burdened by more health symptoms and receive more intensive EoL care than their peers who don’t suffer from loneliness... Loneliness is a pervasive psychosocial phenomenon with profound implications for the health and wellbeing of older adults throughout the life continuum, and particularly at the EoL. One-third of the nearly 2,900 older Americans studied reported loneliness, according to the researchers’ new analysis of Health & Retirement Study data. These individuals had more chronic health symptoms, were more likely to require life support in the last two years of life ... and were more likely to die in an eldercare facility ... than individuals who did not report being lonely. http://bit.ly/2VLGprV


Noted in Media Watch 18 February 2019 (#602, p.11):

- JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online – 14 February 2019 – ‘A practical approach to assessing and mitigating loneliness and isolation in older adults.’ There has been no uniform way of evaluating and documenting loneliness and social isolation as a part of a review of a patient’s social determinants of health. This article provides a framework for healthcare systems, providers, and community members working with older adults to 1) Understand loneliness, isolation, and its counterpart social connection; 2) Describe the different ways loneliness affects health; and, 3) Create a framework for asking about and documenting these experiences. The authors provide guidance on the future of interventions. Abstract: http://bit.ly/2S4KwJX

N.B. Additional articles on the potential detrimental effects on health and well-being of loneliness and isolation noted in 12 November 2018 issue of Media Watch (#589, p.10).

Palliative care data collaborative aims to improve quality

HOSPICE NEWS | Online – 3 March 2020 – Access to quantitative and benchmarked quality data are common expectations of palliative care (PC) providers, health systems, and payers. For more than a decade, three quality measurement registries have met that expectancy: the Global Palliative Care Quality Alliance, the National Palliative Care Registry™, and the Palliative Care Quality Network. As the field has grown, however, the similar approaches and benefits offered by these registries frequently generated confusion among clinicians and did not leverage economies of scale and scope. In recognition of the advantages a one-stop registry can offer, the Palliative Care Quality Collaborative (PCQC) was developed in 2019. The American Academy of Hospice & Palliative Medicine and four other national PC organizations created the PCQC, merging the best aspects of the three registries to serve as the leading voice for quality measurement, benchmarking, reporting, and improvement. http://bit.ly/32O2LdG
Staffing a barrier to palliative care growth

_HOSPICE NEWS_ | Online – 2 March 2020 – While the number of hospices and other organizations providing palliative care (PC) continues to expand nationwide, staffing shortages represent a barrier that threatens to slow this growth. The U.S. has 13.35 hospice and PC specialists for every 100,000 adults 65 and older, according to a 2018 study.¹ The research estimated that by 2040 the patient population will need 10,640 to 24,000 specialists; supply is expected to range between 8,100 and 19,000. Hospice and PC providers also experience shortages in non-physician disciplines, including chaplains, nurses, and social workers. [http://bit.ly/2PI0AmC](http://bit.ly/2PI0AmC)


_N.B._ Additional articles on the status of the PC workforce noted in past issues of Media Watch: 17 February 2020 and 10 June 2019 (#653, p.13, and #617, p.1, respectively).

Who will care for society’s forgotten?

_OREGON | The New York Times_ – 28 February 2020 – Homeless people, when most of us think of them at all, seem to have no past and no future. It is hard to picture them as children who went to school, played games and, I hope, were loved. It is equally hard to imagine that they age, the way all of us do, and get sick, possibly very sick, just like the rest of us. We even rarely think about how they receive medical care – and yet how and whether we treat these patients, especially at the end of their lives, is a moral measuring stick that is all too often missing in our discussions about healthcare in America. Housecall Providers, a home care organization in Portland, provides palliative care to these very vulnerable patients, typically through Medicare, Medicaid or what’s called dual eligibility. [https://nyti.ms/39hf5FW](https://nyti.ms/39hf5FW)

_N.B._ Additional articles on end-of-life care for the homeless in the U.S. noted in 24 February 2020 issue of Media Watch (#654, p.1).

International

Welsh children’s respite care cut due to hospice funding “crisis”

_U.K. (Wales) | BBC News (Cardiff)_ – 4 March 2020 – Funding for Wales’ children’s hospices is reaching “crisis point” amid calls for more public funding to stop them cutting respite care for sick children. They get on average less than 10% of funding from the Welsh Government, lower than for other U.K. countries. The Welsh Government said it was discussing funding needs with hospices. Children’s hospices in Scotland get more than half of their funding from the Scottish government while England’s children’s hospices get 21% of their cash from the public purse. Hospices provide specialist one-to-one care and outreach services to children and their families, including end-of-life and crisis care, plus respite help to full-time carers. The two children’s hospices in Wales, Ty Hafan near Cardiff and Ty Gobaith near Conwy, rely on public donations to survive. But they say uncertainty around funding affects their ability to plan and one said they were “living from hand to mouth, year to year.” Due to the financial strain on the Ty Hafan hospice in Sully, Vale of Glamorgan, the charity said it had been forced to prioritise families with immediate need – so respite care to families has been cut in half. [https://bbc.in/39rARH2](https://bbc.in/39rARH2)

Specialist Publications

‘Emotional communication in home care: A comparison between Norway and Sweden’ (p.7), in _Patient Education & Counseling._

‘Illness-related suffering and need for palliative care in Rohingya refugees and caregivers in Bangladesh: A cross-sectional study’ (p.13), in _Plos Medicine._

‘What it means to be a palliative care volunteer in eight European countries: A qualitative analysis of accounts of volunteering’ (p.14), in _Scandana-vian Journal of Caring Sciences._
Defining a “good death” in the pediatric intensive care unit

AMERICAN JOURNAL OF CRITICAL CARE, 2020;29(2):111-121. Societal attitudes about end-of-life events are at odds with how, where, and when children die. In addition, parents’ ideas about what constitutes a “good death” in a pediatric intensive care unit (ICU) vary widely. A concept analysis was conducted of parents’ views of a good death in the pediatric ICU. Empirical studies of parents who had experienced their child’s death in the inpatient setting were identified through database searches. The concept analysis allowed the definition of antecedents, attributes, and consequences of a good death. Empirical referents and exemplars cases of care of a dying child in the pediatric intensive care unit serve to further operationalize the concept. Conceptual knowledge of what constitutes a good death from a parent’s perspective may allow pediatric nurses to care for dying children in a way that promotes parents’ coping with bereavement and continued bonds and memories of the deceased child. The proposed conceptual model synthesizes characteristics of a good death into actionable attributes to guide bedside nursing care of the dying child. Abstract: http://bit.ly/2TIHbVN

Published Matters

‘Predatory journals: A cautionary tale and a lesson in copyright transfer’ (p.15), in Mayo Clinic Proceedings.

Noted in Media Watch 16 September 2019 (#631, pp.9-10):

- JOURNAL OF PALLIATIVE MEDICINE, 2019;22(9):1149-1153. ‘Top ten tips palliative care clinicians should know about caring for children in neonatal and pediatric intensive care units.’ Over the past several years, pediatric critical care units increasingly count on the expert advisement of palliative care (PC) specialists. Given the limited availability of pediatric PC specialists, all PC clinicians may be required to care for pediatric patients and their families. Special considerations in caring for these patients include the relative importance of prognosis, involvement of child life, music and pet therapy, incorporation of parents in end-of-life rituals, care for siblings, use of medical technology, and prolonged duration of stay. Abstract: http://bit.ly/2krWVNH

Noted in Media Watch 22 July 2019 (#623, p.11):

- JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(4):333-343. ‘Parents’ wishes for what they had or had not done and their coping after their infant’s or child’s neonatal intensive care unit/pediatric intensive care unit/emergency department death.’ Mothers wished they spent more time with the child, chosen different treatments, advocated for care changes, and allowed the child his or her wishes. Fathers wished they had spent more time with the child and gotten care earlier. Mothers wished they had not agreed to child’s surgery/treatment, taken her own actions (self-blame), and left the hospital before the death. Fathers wished they had not been so hard on the child, agreed with doctors/treatment, and taken own actions (self-blame). Abstract: http://bit.ly/2GcuKK9

Noted in Media Watch 24 June 2019 (#619, p.11):

- PEDIATRIC CRITICAL CARE MEDICINE | Online – 14 June 2019 – ‘When a child dies in the PICU: Practice recommendations from a qualitative study of bereaved parents.’ Bereaved parents identified several areas for care delivery and improvement across three time periods. During hospitalization, parents’ recommendations focused on improved communication, changes to the physical environment, better self-care resources, and provision of family support. During the dying phase, parents suggested private, demedicalized rooms, familiar staff members, and support to leave the hospital. Recommendations for care after death focused mainly on the provision of ongoing support from the hospital or local bereavement services. Abstract: http://bit.ly/2Ko3MuV
Impact of length of hospice on spending and utilization among Medicare beneficiaries with lung cancer

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 March 2020 – The study sample was a 10% random sample of Medicare fee-for-service beneficiaries with lung cancer who died between 2010 and 2013. The authors identified different categories of hospice users (hospice enrollment for 1-7 days, 8-14 days, 15-30 days, 31-60 days, 61 days – 6 months) and non-users. They used propensity score matching to match users in each enrollment category with non-users. The outcomes were: 1) Total Medicare spending; 2) Number of hospitalizations; 3) Number of emergency department (ED) visits; 4) Number of physician-administered chemotherapy claims; and, 5) Number of radiation therapy sessions. Hospice users had significantly lower spending, fewer hospitalizations, and fewer ED visits than non-users across all categories of hospice enrollment. Large savings occurred when patients stayed in hospice for at least one month (US$16,566 for those enrolled 61 days – 6 months; US$16,409 for those enrolled 31-60 days). Significant reduction in use of outpatient services including chemotherapy and radiation therapy was observed among patients using hospice for at least 1 month. While cost savings were realized even when hospice is utilized for a short duration, large savings occurred when hospice is used for at least 1 month. Abstract (w. list of references): http://bit.ly/2PI5Oia

Noted in Media Watch 16 September 2019 (#631, p.13):

- THE ONCOLOGIST | Online – 9 September 2019 – ‘Cost and utilization of lung cancer end-of-life care among racial-ethnic minority groups in the U.S.’ Racial-ethnic minority patients with lung cancer experience significantly higher end-of-life care costs and more intense care compared with non-Hispanic white patients, with the greatest differences apparent in costs and utilization related to inpatient care services. Although several broader factors are likely to contribute to this disparity, it is worthwhile to focus in on what types of services, specifically, reveal the greatest cost differences. In this way, care providers can work to better understand this issue at the hospital level and develop more actionable solutions to provide equitable, culturally competent care. Full text: http://bit.ly/2TCPf8A

Noted in Media Watch 2 September 2019 (#629, p.8):

- BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 31 August 2019 – ‘Lung cancer and end-of-life care: A systematic review and thematic synthesis of aggressive inpatient care.’ This study was undertaken to evaluate the literature on aggressive inpatient end-of-life care (EoLC) for lung cancer and analyse the evolution of its aggressiveness over time. Among the 150 articles identified, 42 were retained for review... The percentage of patients subjected to aggressive therapy seems to have increased over time. Early management by palliative care teams seems to limit aggressive care. The authors’ analysis indicated frequent aggressive EoLC for patients with lung cancer, regardless of the definition used. Full text: http://bit.ly/2HCMa3a

“Online training is great but human interaction is better”: Training preferences of Veterans Affairs interdisciplinary palliative care consult teams

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 3 March 2020 – A growing body of research has examined modalities for delivering palliative care (PC) education; however, little is known about education and training preferences of Veterans Affairs interdisciplinary Palliative Care Consult Teams (PCCT). The authors explored training preferences of PCCTs from 46 Veterans Affairs Medical Centers participating in either a multisite webinar or a small group, in-person workshop. They interviewed participants by telephone seven to eight month post-training. In all, 75.9% preferred in-person education and training, including 78.9% of workshop participants and 73.1% of webinar participants. Respondents described in-person training as fostering learning through the following processes: 1) Active engagement and focus; 2) Interaction and networking; 3) Meaning-making and relevance; and, 4) reciprocity and commitment. Although it is not possible for web-based PC education programs to replicate all aspects of the in-person learning experience, building experiential, interactive, meaningful, and reciprocal components into web-based education may help shift preferences and make interdisciplinary team-based PC education accessible to a larger audience. Abstract (w. list of references): http://bit.ly/2VEiRRZ
The life experiences among primary family caregivers of home-based palliative care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 1 March 2020 – Twenty-two primary family caregivers (FCGs) participated this study. Six main themes describing caregivers’ experiences emerged from the interviews: 1) Learning the basic skills of EoL home care; 2) Arranging the sharing and rotation of care; 3) Preparing for upcoming deaths and funerals; 4) Negotiating the cultural and ethical issues of EoL home care; 5) Ensuring a comfortable life with basic life support; and, 6) Maintaining care characterized by concern, perseverance, and patience. Primary FCGs of home-based palliative care (HBPC) need support and must learn home care skills by means of the holistic approach. It is crucial to establish assessment tools for caregivers’ preparedness for HBPC. Abstract (w. list of references): http://bit.ly/2PGSilSt

Related:
- PATIENT EDUCATION & COUNSELING | Online – 2 March 2020 – ‘Emotional communication in home care: A comparison between Norway and Sweden.’ In this study, the authors explored and compared the supportive responses of nursing staff to older persons’ emotions in home care in Norway and Sweden. The Swedish nursing staff provided space for further disclosure of worry more frequently than the Norwegian nursing staff... In all, 65% of the responses were supportive. Multiple logistic regression analyses showed that highly person-centred responses were independently associated with worries phrasing an emotion... The level of person-centredness was associated with the way in which older persons expressed their distress. Abstract: http://bit.ly/2TubjCq

N.B. Different perspectives on dying at home noted in 24 February 2020 issue of Media Watch (#654, pp.2-3).

Medicine’s collision with false hope: The false hope harms argument

BIOETHICS | Online – 5 March 2020 – By not speaking up against unrealistic patient and family requests – including some requests for rights-to-try, resuscitative efforts in terminally ill patients, or other demands for non-beneficial treatments – healthcare providers precipitate harms, i.e., false hope harms (FHH). These harms arise on both individual and communal levels and cannot be ignored. The aim of this article is not to offer a definition of false hope, because the phenomenon of false hope is too complex for any simple definition. The author makes four points while outlining the FHH argument: 1) Consumer medicine and false hope are connected; 2) Providers and patients are very vulnerable in the system of consumer medicine; 3) Providers have a responsibility to stand up against false hope; and, 4) How the FHH argument could perhaps offer a footing to resist giving in to false hope. Full text: http://bit.ly/38tRGjk

Underlying goals of advance care planning: A qualitative analysis of the literature

BMC PALLIATIVE CARE | Online – 6 March 2020 – Within scientific literature, five different underlying goals of advance care planning (ACP) prevail: 1) Respecting individual patient autonomy; 2) Improving quality of care; 3) Strengthening relationships; 4) Preparing for end-of-life; and, 5) Reducing overtreatment. Negotiating which goal prevails in a specific situation, might illuminate which outcomes are in accordance with the chosen goal and which risks need to be considered. Specifying underlying goals may direct the debate on definitions, methods and preferred outcomes of ACP. Full text: http://bit.ly/2vz5jKX

Related:
- ETHNICITY & HEALTH | Online – 4 March 2020 – ‘Advance care planning among ethnic/racial minority older adults: Prevalence of and factors associated with informal talk, durable power of attorney for healthcare, and living will.’ Given the ethnic/racial disparities in end-of-life care, this study describes and identifies factors affecting engagement in three types of advance care planning including informal talk, living will, and durable power of attorney for healthcare among ethnic/racial minority older adults. The results of this study show that informal talk (60%) happened most followed by durable power of attorney for healthcare (30%) and living will (26.5%) completion. Abstract: http://bit.ly/2lnUC7
A troubled care home market should concern us all

BRITISH MEDICAL JOURNAL | Online 4 March 2020 – In December, the healthcare consultancy Laing-Buisson published its 30th annual report on the state of the care home market. Most National Health Service workers won’t have seen it. It won’t make the media outside niche professional outlets. Yet the picture it paints has major implications for the wider healthcare system, future social policy, and wider society. For international readers, care homes in this context encompasses both residential homes (where registered nurses are rarely or sparsely employed) and nursing homes (which employ nurses alongside care assistants). Care homes are also sometimes referred to by other names such as “long term care (LTC) facilities” or “hostels” in other nations. Although some care homes specialise in the care of younger adults with physical, mental, or learning disabilities, most residents enter towards the end of the ageing process. By this stage they generally have severe frailty, age related disability, multiple long-term conditions, and often dementia. The threshold for entry has become progressively higher, with the aging demographic of our population not matched by an expansion in care home places. Many older people who would have entered LTC in years past are now supported in their own home or have housing designed for their needs. So why should we care what market reports show? Around 410 000 people are in care homes in the U.K. in around 11 300 homes, with a total market of around £16 billion. This is almost three times the number of people in hospital beds. Many of us will die in care homes. Admissions to acute hospitals from them are far higher than they are from among people of the same age living outside of them. Full text: http://bit.ly/2VMkD7t


Noted in Media Watch 2 March 2020 (#655, p.10):

- JOURNAL OF POST ACUTE & LONG-TERM CARE MEDICINE | Online – 27 February 2020 – ‘Palliative care implementation in long-term care facilities: European Association for Palliative Care White Paper.’ This is the first study the authors are aware of that has formulated recommendations on strategies for implementation of palliative care (PC) interventions in long-term care facilities (LTCFs) based on international research with experts. The recommendations aim to guide how PC can be introduced, embedded and sustained in LTCFs. 18 international experts from 15 countries participated in a Transparent Expert Consultation (TEC) workshop. The TEC study offers a framework of recommendations at each level in which strategies can be implemented and has outlined the processes involved, although the authors acknowledge that change is unlikely to be linear. Full text: http://bit.ly/2wicpcg

N.B. Selected articles on the home care market in the U.K. noted in 26 November 2018 issue of Media Watch (#591, pp.2-3). Additional articles on end-of-life and PC in LTCFs noted in this issue of Media Watch.

A mixed methods approach of end-of-life care, social rites, and bereavement outcomes: A transnational perspective

CULTURE, MEDICINE & PSYCHIATRY | Online – 2 March 2020 – This article focuses on examining the potential benefits of the end-of-life (EoL) informal caregiving, communication, and ritualistic behaviors in adaptation to the conjugal bereavement across two different cultural-background contexts: France and Togo, West Africa. The investigation adopted a transnational approach including a total of 235 bereaved spouses. Despite the variation in the length of time since death, no significant difference was found between the Togolese and French bereaved with respect to the level of complicated grief symptoms. However, the Togolese bereaved perceived a significant post-loss growth, fostered by EoL communication with the dying and the performance of ritualistic behaviors. In the French sample, bereaved individuals who had experienced more intimate communication with their dying spouse reported a high level of post-loss growth. Moreover, findings showed that EoL caregiving without ritualistic support or communication is associated with poor post-bereavement outcomes. These findings suggest a clinical need to promote informal caregiving to the dying, communication with the dying, and ritualistic support during the process of dying as entangled components of EoL care. Abstract (w. list of references): http://bit.ly/32QrDBu
Improving drug therapy for patients with life-limiting illnesses: Let’s take care of some low hanging fruit

Prescribing statins, AChEIs, anticoagulants, and intensive treatment of diabetes and hypertension are neither evidence based nor consistent with a person-centered approach to care of people with life-limiting illnesses. A variety of strategies might address the current situation. At the facility or office level, quality improvement initiatives can include protocols to identify, reevaluate, and deprescribe these drugs in patients with life-limiting illness. Hospitals, health systems, and nursing home chains can provide leadership, oversight, and support for focused quality improvement initiatives, and leverage the efficient use of electronic health records to identify and send reminders to prescribers about the lack of evidence for the use of these drugs in patients with life-limiting illness. There are many competing priorities for quality improvement initiatives, and there is always a concern about alert fatigue from numerous reminders from the electronic record. However, given the lack of evidence, potential harm, and excess costs, deprescribing these drugs in patients with life-limiting illnesses should be a priority. An interprofessional approach is essential to these efforts, involving the patient (and healthcare proxy when appropriate), nursing staff, pharmacists, psychologists, physicians, nurse practitioners, and physician assistants, and strong leadership from facility and office practice medical directors. Full text: http://bit.ly/2wzMxZy

Wish to die in older patients: Development and validation of two assessment instruments

The wish to die may be different in geriatric patients than in younger terminally ill patients. This study aimed to develop and validate instruments for assessing the wish to die in geriatric patients. The Schedule of Attitudes Toward Hastened Death (SAHD) was adapted to the older population (SAHD-Senior). A second tool was developed based on qualitative literature, the Categories of Attitudes Toward Death Occurrence (CADO). After cognitive pretesting, these instruments were validated in a sample of patients admitted to a geriatric rehabilitation unit. The SAHD-Senior showed good psychometric properties and a unifactorial structure. In the studied sample, 12.9% had a SAHD-Senior score of 10 or higher, suggesting a significant wish to die. Associations were observed between high levels of the SAHD-Senior and advanced age, high levels of depressive symptoms, lower quality of life, and lower cognitive function. The CADO allowed for passive death wishes to be distinguished from wishes to actively hasten death. According to the CADO, 14.9% of the sample had a wish to die. The wish to die in older patients admitted to rehabilitation can be validly assessed with two novel instruments. Abstract: http://bit.ly/32CBUBg

Related:
- **PALLIATIVE & SUPPORTIVE CARE** | Online – 5 March 2020 – ‘Communication about the desire to die: Development and evaluation of a first needs-oriented training concept: A pilot study.’ Patients’ desire to die (DD) is rarely discussed in palliative care due to health professionals’ (HPs) feeling of uncertainty. The aim of the study was to develop and evaluate a training to increase HPs’ self-confidence in responding professionally to patient’s DD. The developed training on addressing DD meets a need and was perceived by the participants to be of added value. Future research should measure training effects with a validated instrument, including more participants, diverse participant groups, and a control group. Abstract (w. list of references): http://bit.ly/2Ttd2Jz

Noted in Media Watch 5 March 2018 (#553, p.12):
- **PSYCHO-ONCOLOGY** | Online – 28 February 2018 – ‘Assessment of the wish to hasten death in patients with advanced cancer: A comparison of two different approaches.’ The Desire for Death Rating Scale (DDRS) and the short form of the Schedule of Attitudes Toward Hastened Death (SAHD-5) are different approaches to assessing the wish to hasten death (WTHD). Concordance between the DDfRS and SAHD-5 in identifying individuals with an elevated WTHD was poor when using recommended cut-off scores, but could be improved by using different thresholds. Only 4 patients regarded the assessment questions as bothersome, and 90.6% considered it important that healthcare professionals inquire about the WTHD. Abstract: http://bit.ly/2uJ8XY3

N.B. Additional articles on the WTHD noted in 2 March 2020 issue of Media Watch (#655, pp.11-12).
Underneath the white coat: Risk and protective factors for palliative care providers in their daily work

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2020;22(2):108-114. Palliative care (PC) practice is associated with risk factors linked to end-of-life, chronicity, personal, interpersonal, and work characteristics, as well as with protective factors, but how these are perceived by the healthcare providers themselves is not clear. This article elaborates a theoretical framework explaining the risk and protective factors for PC providers in their daily practice. From interviews, 28 codes, subsequently organized into 11 interconnected categories, emerged. They described both stressors (emotion management regarding death/dying, conflicts, communication and relationship with patients/caregivers, discrepancies between patients’ and caregivers’ needs, communication of poor diagnosis/prognosis, decision-making about treatment, and real-life and work interference) and protective factors (social support, positive approach and value of past experience, recognized value of/passion toward professional work, work-family balance). Experiencing these elements as positive or negative depends on the professionals’ point of view, as well as their past and present experience. Understanding what dealing with life-limiting illnesses means may suggest tailored interventions to improve professionals’ well-being by fostering the protective elements and combating the risk factors. Abstract: http://bit.ly/3cmrKt2

N.B. Additional articles on PC providers’ resilience and well-being noted in 2 March 2020 issue of Media Watch (#655, p.5).

Home-based pediatric palliative care and electronic health: Systematic mixed methods review

JOURNAL OF MEDICAL INTERNET RESEARCH, 2020;22(2):e16248. The scarce amount of research in the area involving eHealth-supported, home-based pediatric palliative care (PC) and the methodological and ethical challenges involved affected the conclusions that could be drawn from this mixed methods review. The results in the primary studies were mainly based on information from healthcare providers. For eHealth to complement pediatric PC at home, research needs to identify the needs and wishes of both children and their families. eHealth poses many possible advantages and can play an important role in home-based pediatric PC. If measures are not taken to establish a consensus on satisfactory research methods, then eHealth technology may be implemented without undergoing proper evaluation. The findings of this review can specially inform future research through the need for a prioritization of research within eHealth to support home-based pediatric PC, because of the limited knowledge regarding the affected children and their families’ needs and wishes concerning eHealth. There is a need to develop research strategies to reduce unnecessary burdens on the children and their caregivers and simultaneously strive to optimize the study design. Full text: http://bit.ly/2TVGgqXV

Noted in Media Watch 13 January 2020 (#648, p.7):

- BRITISH JOURNAL OF GENERAL PRACTICE, 2020;70(690):e20-e28. ‘Electronic coordination for end-of-life care.’ Quality palliative care depends on recording, sharing, and acting on patients’ needs and preferences, such as their wishes about resuscitation and their preferred place of death. An electronic care coordination system known as KIS (Key Information Summary) was evaluated in Scotland using data from over 1,300 deceased patients. The study found that patients with a KIS record were twice as likely to die in the community, as they wished, rather than in hospital, and most had a record of their desired resuscitation status. Patients with frailty and dementia frequently had a KIS recorded a year or more before their death. Full text: http://bit.ly/37XqytT

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
Healthcare providers’ views on the transition between hospital and primary care in patients in the palliative phase: A qualitative description study

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 2 March 2020 – Inadequate handovers between hospital and home can lead to adverse health outcomes. A group particularly at risk are patients at the end of life (EoL) because of complex health problems, frequent care transitions and involvement of many professionals. In this descriptive qualitative study, the following themes emerged: 1) Lack of identification of and communication about the last phase of life; 2) Incomplete and insufficient handover; and, 3) Uncertainty about responsibilities. Professionals emphasize the importance of proper handovers and transitional processes in these vulnerable patients. The transition between hospital to primary care is hindered by a lack of identification of the palliative phase and uncertainties about patient awareness. Direct communication between professionals is needed but lacking. The handover itself is currently primarily focussed on physical aspects where psychosocial aspects were also found necessary. Furthermore, uncertainties with regard to physicians’ responsibility for the patient seem to further hinder professionals in the transitional process. Abstract (w. link to references): http://bit.ly/2VG7JrC

Noted in Media Watch 6 January 2020 (#647, p.2):

- JOURNAL OF PALLIATIVE MEDICINE | Online – 31 December 2019 – ‘Healthcare worker perceptions of gaps and opportunities to improve hospital-to-hospice transitions.’ Three areas of gaps in hospital-to-hospice transitions were identified in interviews with healthcare workers from three hospitals and three hospice programs: 1) Low literacy about hospice care; 2) Changes in medications; and, 3) Hand-off information related to daily care. Specific concerns included hospital providers giving inaccurate descriptions of hospice; discharge orders not including comfort medications for the transition and inadequate prescriptions to manage medications at home; and lack of information about daily care hindering smooth transition and continuity of care. Abstract: http://bit.ly/2trNcL4

Palliative care and the tragedy of the commons

JOURNAL OF PALLIATIVE CARE | Online – 5 March 2020 – Many of the paradoxes of end-of-life care (EoLC), including the combination of overtreatment and low quality of life (QoL), can be explained in part by the fact that the structure of EoLC is a tragedy of the commons, where no one provider “owns” the patient or is responsible for the outcomes of treatment. This article outlines the way in which applying frameworks from economics to EoLC can contribute to conversations about reform, particularly in terms of how to reform palliative care to harness its full potential to limit overtreatment, improve QoL, and lower costs. The authors use principles from economics and political science to propose a series of possible reforms to EoLC, starting with reimbursement bundling and ending with pause points and more conscious ownership of care decisions by patients and their teams of providers. Abstract (w. list of references): http://bit.ly/2VLvHBN

To what extent does clinically assisted nutrition and hydration have a role in the care of dying people?

JOURNAL OF PALLIATIVE CARE | Online – 4 March 2020 – The question over whether to administer clinically assisted nutrition and hydration (CANH) to a dying patient is controversial, with much debate concerning this sensitive issue. The administration of CANH poses clinical and ethical dilemmas, with supporting and opposing views. Proposed positive effects of CANH include preventing thirst, delirium, hypercalcemia, and opioid toxicity. However, CANH has been shown to increase the risk of aspiration, pressure ulcers, infections, and hospital admissions as well as potentially causing discomfort to the patient. Guidance from several national bodies generally advises that the risks and burdens of CANH outweigh the benefits in the dying patient. However, an individualized approach is needed, and the patient’s wishes regarding CANH need consideration if they have capacity and can communicate. Otherwise, sensitive discussions are required with the family, enquiring about the patient’s prior wishes if there is no advanced care plan and acting in the patient’s best interests. The ethical principles of autonomy, beneficence, non-maleficence, and justice need to be applied being mindful of any cultural and religious beliefs and potential misperceptions. Abstract (w. list of references): http://bit.ly/32QCMm2
Hospice staff perspectives on caring for people with dementia: A multi-site, multi-stakeholder study

JOURNAL OF PALLIATIVE MEDICINE | Online – 4 March 2020 – In the U.S., 45% of people enrolled in hospice have dementia. Little is known about how hospice professionals facilitate preference-aligned end-of-life care for people with dementia (PWD) and their families. Four themes regarding caring for PWD in hospice were identified. 1) Dementia prevalence in hospice is increasing and some hospices are developing programs to accommodate specific needs; 2) Setting impacts discussions of preferences and care decisions; 3) Caring for PWD on hospice poses unique challenges caused by perceptions that dementia is not terminal, a lack of advance care planning discussions before hospice admission, and proxy decision-makers who were inadequately prepared for their role; and, 4) Hospice regulatory and policy changes disproportionately impact PWD. Hospice professionals perceive increasing demand for, and multilevel challenges to, caring for PWD. Abstract: http://bit.ly/2TSFqDV

Noted in Media Watch 2 March 2020 (#655, p.6):

- CLINICS IN GERIATRIC MEDICINE | Online – 20 February 2020 – 'Palliative care for dementia: 2019 update.' Dementia management is complicated by neuropsychiatric symptoms such that the longitudinal care of a psychiatrist or other mental health provider is often an essential part of patient care and a major source of family support. Given the importance of end-of-life continuity of care, the involvement of psychiatry in palliative and hospice services affords an important opportunity for growth. Common challenges involve sharing prognostic information with patients and families to aid in advance planning, and management of persistent pain and nutritional issues. Future research will yield important new insights and guidelines for care. Abstract (w. link to references): http://bit.ly/2wNiH40

N.B. Additional articles on hospice and end-of-life care for people living with dementia noted in this issue of Media Watch.

Should patients who are incarcerated on death row receive palliative cancer care?

THE LANCET ONCOLOGY, 2020;21(3):P337-P338. In modern society, it is accepted that individuals have the right to die with dignity. Since 1976, in the U.S., people who are incarcerated have a limited constitutional right to healthcare, consistent with the Eighth Amendment [to the U.S. Constitution]. At present, there are more than 2,600 incarcerated men and women in the U.S. who have been sentenced to death, most of whom have less than a high school diploma or High School Equivalency Certificate, and are disproportionately of minority racial or ethnic backgrounds (42% African American representation on death row vs 13% African American representation in the U.S. census). Abstract (w. list of references): http://bit.ly/2PGBqgL

Noted in Media Watch 2 May 2016 (#460, p.13):

- DEATH STUDIES | Online – 19 April 2016 – ‘Assisted suicide for prisoners? Stakeholder and prisoner perspectives.’ For a wider project on aging in prison, the authors interviewed 35 older prisoners and 24 stakeholders (prison staff, prison healthcare professionals, and policy makers) about healthcare for prisoners. In all, 6 prisoners and 3 stakeholders spontaneously expressed their attitudes concerning assisted suicide. Some prisoners seek assisted suicide for medical reasons and others because they regard spending the rest of their lives in prison as undignified. This article presents these perspectives on assisted suicide in prison and provides an ethical analysis of the issues raised. Abstract: http://bit.ly/2vBvvdU
End-of-life therapy: Palliative care instead of palliative scare

**MEMO – MAGAZINE OF EUROPEAN MEDICAL ONCOLOGY** | Online – 3 March 2020 – In this issue of MEMO a series of short reviews update important issues concerning end-of-life care of patients suffering from incurable diseases. Palliative care aims to provide symptom control, relieve anxiety and depression and also decrease stress levels of patients and their relatives. **Journal contents page:** [http://bit.ly/2TsMCY4](http://bit.ly/2TsMCY4)

**Case report**

**What are two days worth? Facing dilemmas together at the end of life**

**NEW ENGLAND JOURNAL OF MEDICINE**, 2020;382(10):890-891. Palliative sedation holds unique meaning for clinicians, even those accustomed to providing care at the end of life. Although its goal is always control of refractory symptoms, we should all take pause when recommending it. In one national survey, most palliative care providers said they believed that its use was ethically appropriate, but a substantial proportion reported feeling distressed when recommending it to patients. It should be a treatment of last resort for a patient whose suffering cannot be relieved by any other means. For many specialist-level palliative care providers, it is a procedure done only in extreme circumstances, and many clinicians don’t endorse its use at all for existential suffering. **Access article at:** [http://bit.ly/2POQSPu](http://bit.ly/2POQSPu)

N.B. Additional articles on palliative (or terminal:) sedation noted in 2 March 2020 issue of Media Watch (#655, p.9).

**Illness-related suffering and need for palliative care in Rohingya refugees and caregivers in Bangladesh: A cross-sectional study**

**PLOS MEDICINE** | Online – 3 March 2020 – Despite recognition that palliative care (PC) is an essential component of any humanitarian response, serious illness-related suffering continues to be pervasive in these settings. There is very limited evidence about the need for PC and symptom relief to guide the implementation of programs to alleviate the burden of serious illness-related suffering in these settings. A basic package of essential medications and supplies can provide pain relief and PC; however, the practical availability of these items has not been assessed. This study describes the illness-related suffering and need for PC in Rohingya refugees and caregivers in Bangladesh. **Full text:** [http://bit.ly/2PLF68B](http://bit.ly/2PLF68B)

Noted in Media Watch 9 December 2019 (#643, pp.5-6)

- **EUROPEAN ASSOCIATION OF PALLIATIVE CARE BLOG** | Online – Accessed 2 December 2019 – ‘A Field Manual for Palliative Care in Humanitarian Crises.’ Recently, there has been increasing recognition of the importance of integrating palliative care (PC) into humanitarian aid. This is reflected in a growing number of journal articles and position papers on this topic, most notably with the publication of the World Health Organization guide.¹ This increasing recognition is in part a reflection of the growth of PC as a medical subspecialty; it also reflects the increasing understanding that the goal of humanitarian aid is not simply to save lives, but also to alleviate suffering. **Download/view introduction to manual at:** [http://bit.ly/2YcNJFJ](http://bit.ly/2YcNJFJ)

¹ ‘Integrating palliative care and symptom relief into responses to humanitarian emergencies and crises,’ World Health Organization, October 2018. [Noted in 1 October 2018 issue of Media Watch (#583, p.6)]


N.B. Additional articles on PC in humanitarian crises noted in this issue of Media Watch.
Noted in Media Watch 21 October 2019 (#636, p.4):

- **BANGLADESH | New Zealand Herald – 15 October 2019 – ‘Whangārei health professionals to help at world’s largest refugee settlement in Bangladesh.’** For Walter Nasarek, it will be his second time to Bangladesh on medical duties but the sheer scale of providing palliative care to community health field workers in the world’s largest refugee settlement isn’t lost on him. The staff member at North Haven Hospice in Whangārei, together with palliative medicine specialist Dr. Kees Lodder, flew out on Sunday for two and a half weeks to help other health professionals at the refugee camp in Cox’s Bazar, southeast Bangladesh. The camps are spread over more than 14km and house more than 1 million Rohingya refugees displaced from Burma. [http://bit.ly/2MIHACi](http://bit.ly/2MIHACi)

Noted in Media Watch 26 August 2019 (#628, p.5):

- **BANGLADESH | The New Humanitarian – Accessed 19 August 2019 – ‘The healer: In Rohingya camps, a local response reaches untreated refugees.’** There are nearly 100 non-governmental organizations, United Nations’ agencies, or government bodies working on the massive refugee response in Bangladesh’s Rohingya camps. But only one – a tiny local organisation – is focused on the neglected field of palliative care (PC). The Dhaka-based Fasiuddin Khan Research Foundation treats people with life-threatening or severe chronic illnesses in their homes – finding hard-to-reach patients who can’t access hospitals or clinics in the sprawling camps. Proponents say it’s the first PC programme in any humanitarian response. [http://bit.ly/2TK0ziZ](http://bit.ly/2TK0ziZ)

What it means to be a palliative care volunteer in eight European countries: A qualitative analysis of accounts of volunteering

*SCANDANAVIAN JOURNAL OF CARING SCIENCES | Online – 6 March 2020 –* The authors explore the experiences of volunteers in hospice and palliative care (HPC) from their insider perspective, to understand why volunteers choose to work in this field and to understand what it means to them to be involved in palliative care (PC) in this way. Stories were collected by the European Association for Palliative Care Task Force for Volunteering contacts in each of the eight countries. The majority of stories came from volunteers involved in different settings including adult patient’s homes, hospices, hospitals and care homes. Volunteers were asked two questions: “What do you do as a volunteer? and “What does volunteering mean to you?” Three themes were identified: 1) What volunteers do; 2) How volunteers approach their work; and; 3) What working in HPC means to volunteers. The analysis revealed that common approaches to addressing and describing HPC volunteering in terms of tasks and roles could be expanded. To volunteers, it is not about tasks, but about a part of their life, the impact upon which can be significant. **Abstract:** [http://bit.ly/2PTbw0S](http://bit.ly/2PTbw0S)

Noted in Media Watch 24 February 2020 (#654, p.13):

- **PALLIATIVE MEDICINE | Online – 17 February 2020 – “It’s not what they were expecting”: A systematic review and narrative synthesis of the role and experience of the hospital palliative care volunteer.’** The volume of research evidence in the studies that were included in this review, and that describe volunteers’ actions of “being with” terminally ill patients, highlights not only the importance of this aspect of volunteer work but also exemplifies the aspects of volunteers’ role they found most satisfying. Ideally, the patient-volunteer relationship would be determined as a result of a process of specifically matching volunteers to patients according to measures of personal compatibility and consideration of relational chemistry. **Full text:** [http://bit.ly/2vFhE5E](http://bit.ly/2vFhE5E)

Noted in Media Watch 10 December 2018 (#593, p.8):

- **BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 7 December 2018 – ‘The liminal space palliative care volunteers occupy and their roles within: A qualitative study.’** Volunteers have an important place in palliative care (PC), positively influencing quality of care for seriously ill people and those close to them and providing a link to the community. However, it is not well understood where volunteers fit into PC provision or how to support them adequately. The authors describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people. Two volunteer roles were identified. The first was “being there” for the dying person. The second was the “liaison” role. **Abstract:** [http://bit.ly/2XEbMoy](http://bit.ly/2XEbMoy)
Publishing Matters

Predatory journals: A cautionary tale and a lesson in copyright transfer

MAYO CLINIC PROCEEDINGS, 2020;95(3):441-444. Predatory journals pose a considerable threat to residency training and subsequent professional development. In addition to the skills gained from conducting research and writing a manuscript, the peer-review process in and of itself provides value to the trainee. The peer-review process offers rigorous evaluation of scientific methods and writing from individuals within medicine, pharmacy, or other disciplines, depending on the journal category. In our case, on initial rejection, suggestions for extensive changes to the study methods and statistical considerations were provided. These comments allow the trainee to reflect on and further enhance the science and manuscript for a higher quality publication. This value is diminished or absent when a manuscript is submitted to a predatory journal that may have a peer-review process of questionable integrity or no peer review at all. Full text: https://mayocl.in/2vF4ztt

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Something Missed or Overlooked?

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

Media Watch: Access on Online

International


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PALLIATIVE CARE RESEARCH NETWORK: http://bit.ly/2E1e6LX
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U.K. | Omega, the National Association for End-of-Life Care: http://bit.ly/2MxVir1

South America

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