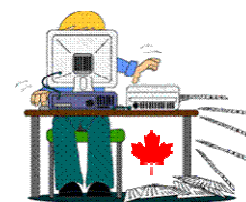


Media Watch...

is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them abreast of current, emerging and related issues – and, to inform discussion and encourage further inquiry.

6 January 2020 Edition | Issue #647



Compilation of Media Watch 2008-2020 ©

Compiled & Annotated by Barry R. Ashpole

Research in ambulatory primary care settings has found that ethno-cultural discordance between patient and provider is associated with lower relational and management continuity, suggesting a reduced level of trust.

'Advance care planning and decision-making in a home-based primary care service in a Canadian urban centre' (p.5), in *Canadian Geriatrics Journal*.

U.S.A.

Improving health literacy could boost access to hospice, palliative care

HOSPICE NEWS | Online – 2 January 2020 – A lack of health literacy may pose a barrier to patients receiving hospice or palliative care (PC), including delaying their entry into hospice. Patients who lack an understanding of healthcare information or terminology, do not understand their own illnesses, or who misconstrue the nature of hospice or PC may lack the necessary tools to make an informed decision about their end-of-life wishes. Health literacy is the degree to which individuals can obtain, process and understand basic health information and services needed to make appropriate health decisions, according to the Institute of Medicine. A health illiterate patient may have a strong overall ability to read or have an advanced education but have a limited understanding of information specific to healthcare. As many as one-third of Medicare enrollees have a low-level of health literacy, and

research indicates that this increases across-the-board healthcare costs by as much as 5% annually. <http://bit.ly/2trBWYE>

Specialist Publications

“‘It’s like a death sentence but it really isn’t.’ What patients and families want to know about hospice care when making end-of-life decisions’ (p.2), in *American Journal of Hospice & Palliative Medicine*.

‘A national study of end-of-life care among older veterans with hearing and vision loss’ (p.7), in *Journal of the American Geriatrics Society*.

‘Healthcare worker perceptions of gaps and opportunities to improve hospital-to-hospice transitions’ (p.2), in *Journal of Palliative Medicine*.

Cont. next page



Share this issue of Media Watch with a colleague

Noted in Media Watch 6 March 2017 (#502, p.7):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(6):544-549. ‘**The impact of health literacy on palliative care outcomes.**’ Limited health literacy is a recognized health problem often leading to poorer health outcomes. Healthcare professionals, including nurses, are responsible for delivering health information in a clear and understandable way. Yet nurses may overestimate patients’ health literacy and miss opportunities to help patients understand and then incorporate medical information. Health outcomes may improve when nurses recognize potential barriers to health literacy and use evidence-based interventions. A review of current research regarding health literacy is provided to assist nurses with communication strategies in their delivery of palliative care. **Abstract:** <http://bit.ly/2sG50SP>

Noted in Media Watch 6 February 2017 (#498, p.16):

- *PRACTICAL RADIATION ONCOLOGY* | Online – 27 January 2017 – ‘**Online palliative care and oncology patient education resources through Google: Do they meet national health literacy recommendations?**’ The authors assessed the readability levels of online palliative care (PC) patient education resources using readability algorithms widely accepted in the medical literature. Ten terms were individually searched: PC, hospice, advance directive, cancer pain management, treatment of metastatic disease, treatment of brain metastasis, treatment of bone metastasis, palliative radiation therapy, palliative chemotherapy, and end-of-life care. Most PC education articles readily available on Google are written above national health literacy recommendations. **Abstract:** <http://bit.ly/2QjrOkr>

Specialist Publications

“It’s like a death sentence but it really isn’t.” What patients and families want to know about hospice care when making end-of-life decisions

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 31 December 2019 – This study highlights where patients’ and families’ understanding could be enhanced to assure that they have the opportunity to benefit from hospice, if they so desire. The Institute of Medicine has stated that better shared decision-making is necessary for patients and families faced with end-of-life decisions.¹ The four key decisional themes highlighted in this article – 1) What is hospice care?; 2) Why might hospice care be helpful?; 3) Where is hospice care provided?; and, 4) How is hospice care paid for? – offer tangible touch points that hospice providers can focus on when initiating conversations and shared decision-making around hospice care. These themes may provide a framework to design patient-centered interventions designed to improve communication around hospice decision-making. **Full text:** <http://bit.ly/36efoQm>

Healthcare worker perceptions of gaps and opportunities to improve hospital-to-hospice transitions

JOURNAL OF PALLIATIVE MEDICINE | Online – 31 December 2019 – Three areas of gaps in hospital-to-hospice transitions were identified [in interviews with healthcare workers from three hospitals and three hospice programs in Portland, Oregon]: 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. The authors identify gaps and suggest opportunities that will serve as the basis for future interventions to design safe and high-quality hospital-to-hospice care transitions. **Abstract:** <http://bit.ly/2trNcL4>

1. ‘Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,’ Institute of Medicine (of the National Academy of Sciences), September 2014. [Noted in 22 September 2014 issue of Media Watch (#376, p.4)] **Full report:** <http://bit.ly/2GeVXNO>

Cont. next page



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

Noted in Media Watch 30 December 2019 (#646, p.9):

- *JOURNAL OF THE AMERICAN GERIATRIC SOCIETY* | Online – 27 December 2019 – ‘**Hospice utilization in the U.S.: A prospective cohort study comparing cancer and non-cancer deaths.**’ Hospice utilization rate was 52.4% for the patient population studied with 70.8% for cancer deaths and 45.4% for non-cancer deaths. Findings suggest hospice remains underutilized, especially among individuals with non-cancer illness. Extrapolating results to the U.S. population, the authors estimate that annually nearly a million individuals who are likely eligible for hospice die without its services. Most (84%) of these decedents have a non-cancer condition. Interventions are needed to increase appropriate hospice utilization, particularly in non-cancer care settings. **Abstract:** <http://bit.ly/378HU5Y>

Experiences at the end of life from the perspective of bereaved parents: Results of a qualitative focus group study

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 30 December 2019 – Palliative care principles are known to support the experiences of children and their families throughout the illness trajectory. However, there is little knowledge of the parental perceptions of care delivered and gaps experienced by families receiving end-of-life care (EoL) care. The authors report the most helpful aspects of care provided during the EoL and identify opportunities to improve care delivery during this critical time. This study consists of two one-hour focus group sessions with 6 participants each facilitated by a clinical psychologist to explore the experiences of bereaved parents of pediatric oncology patients at the end of their child’s life. Four common themes were identified: 1) Valued communication qualities; 2) Valued provider qualities; 3) Unmet needs; and, 4) Parental experiences. The most prevalent of these themes was unmet needs... Parents described struggling with communication from providers, loss of control in the hospital environment, and challenges associated with transition of care to hospice services. Interventions that support the complex needs of a family during EoL care are needed, especially with regard to coordination of care. **Abstract (w. list of references):** <http://bit.ly/2MFK2KF>

Noted in Media Watch 30 December 2019 (#646, p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 27 December 2019 – “‘**There’s just no way to help, and they did.**’ **Parents name compassionate care as a new domain of quality in pediatric home-based hospice and palliative care.**’ Parent-prioritized thematic codes mapped nine of the ten provider-prioritized domains of quality home-based hospice and palliative care; none mapped to the domain “Ethical and Legal Aspects of Care.” Although most of the provider-prioritized domains are pertinent to parents, parents defined these domains differently, deepening understanding and perspective of quality within each domain. An 11th domain, Compassionate Care, was created and defined based on emergent themes. **Abstract:** <http://bit.ly/2t6eG9c>

Noted in Media Watch 22 July 2019 (#623, p.13):

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 19 July 2019 – ‘**Children’s unmet palliative care needs: A scoping review of parents’ perspectives.**’ Children with life-limiting conditions often have complex needs, making it challenging for services to provide satisfactory care. Few studies consider whether services actually meet families’ needs by exploring and identifying the parents’ perspectives of unmet needs. Fifty-five papers met the authors’ scoping review criteria. The findings suggest many unmet needs from the parent’s perspective, across several aspects of the Quality Standards & Children’s Palliative Care Frameworks. Further research is needed which explores the parent’s unmet needs in palliative care services. **Abstract:** <http://bit.ly/2O7CtQ6>

Noted in Media Watch 15 July 2019 (#622, p.8):

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

End-of-life decision making by Austrian physicians: A cross-sectional study

BMC PALLIATIVE CARE | Online – 4 January 2020 – In 2014, the Austrian parliament set up a commission to study “dignity at the end of life.” The result was a position paper containing a total of 51 recommendations, one of which was a call to expand hospice and palliative care (PC) programs in Austria. Partially as a result of very detailed free-text answers, the present study reinforces the recommendation of the Study Commission of the Austrian Federal Chancellery that the reach of PC in Austria should be extended and that medical, ethical and legal training relating to the treatment of dying patients should be improved. Almost 50% of the physicians that participated in this survey felt legally insecure when treating end-of-life (EoL) patients. It appears that many doctors regard the legal consequences of EoL medical treatments as ambiguous. These concerns should be taken into consideration in specifically designed training courses. Furthermore, this study should encourage follow-up projects dealing with the implementation of palliative healthcare concepts in in- and out- patient care, as well as nursing institutions. Further research projects should examine existing communication instruments such as patient decrees, health-care proxies, advance care planning and the “provision dialogue” developed for nursing homes under the auspices of Hospice Austria. These projects should determine the acceptance of such tools in society, as well as their implementability and relevance in everyday life, but also identify possible failings. The low [survey] response rate may be seen as an expression of the reluctance of physicians to openly discuss such subjects as dying, death and associated demands for measures to end lives prematurely. Studies such as the present one may contribute towards actively ensuring the subject is placed on the agenda of specialist conferences and symposiums. **Full text:** <http://bit.ly/2rTC9tQ>

Rehabilitation in palliative care: A qualitative study of team professionals

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 30 December 2019 – The concept of rehabilitative palliative care (PC) has been advocated to help patients preserve function and independence, through greater patient enablement and self-management. Such an approach requires engagement from all members of the PC team. There is a lack of understanding of such viewpoints. The objective of this research was to explore hospice-based PC professionals’ understanding and perceptions of rehabilitation. Overall, participants in this study clearly articulated the underlying values and benefits of rehabilitative PC. Emphasis was placed on ensuring that rehabilitation was appropriately tailored to each individual patient. There was more ambiguity regarding the pragmatic implementation of rehabilitative PC, with a number of barriers and facilitators identified. **Abstract:** <http://bit.ly/2Qb5BF8>

Noted in Media Watch (#633, p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 September 2019 – ‘**Top ten tips palliative care clinicians should know about physical medicine and rehabilitation.**’ This article, written by a team of physical medicine and rehabilitation (PM&R) and palliative care (PC) specialists, aims to help the PC team ... expand their toolkit for treating musculoskeletal and neurological symptoms, improve prognosis for patients with brain and spinal cord injuries, and decide when patients may benefit from PM&R consultation and support. There is significant overlap between the populations treated by PM&R and PC. Better integration between these specialties will help patients to maintain independence as well as advance excellent patient-centered care. **Abstract:** <http://bit.ly/2lxH54o>



[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>

Advance care planning and decision-making in a home-based primary care service in a Canadian urban centre

CANADIAN GERIATRICS JOURNAL, 2019;22(4):182-189. The authors of this study found that some elements of advance care planning (ACP) documentation (e.g., resuscitation status) appear to be widely adopted, while other elements that should be important components of ACP (e.g., information about frailty stage, substitute decision-maker identification, and status regarding preferences for hospitalization) have substantial missing data. Preferences for do not resuscitate and do not hospitalize were relatively high in this population compared to nursing home populations, possibly related to the model of home-based primary care. Consistent with prior research, the authors also found that language and cultural differences appear to influence patients' preference for hospital care. Further research on cross-cultural communication in the ACP process and practice change interventions to improve cross-cultural communication with robust evaluations of their effect are important future activities given the growing number of ethnically diverse frail seniors in Canada's urban centres. **Full text:** <http://bit.ly/2Q9t9dk>

Related:

- *JOURNAL OF PALLIATIVE CARE* | Online – 30 December 2019 – '**A retrospective study reviewing interprofessional advance care planning group discussions in pulmonary rehabilitation: A proof-of-concept and feasibility study.**' Discussing matters relevant to advance care planning (ACP), including providing information about ACP, and sharing fears, wishes, values, and trade-offs were well received in a supportive group environment. Given that 80% of Canadians understand the importance and implications of ACP and that less than 44% of these individuals have discussed their end-of-life wishes with a family member or loved one, an approach that empowers patients while destigmatizing and educating patients about ACP is required. **Full text:** <http://bit.ly/39xxJtR>

Grief memoirs: The familiarity of helping professionals with the genre and its potential incorporation into grief therapy

DEATH STUDIES | Online 2 – January 2020 – The grief memoir is a fast-developing genre that in recent decades has become a popular form of public mourning and self-therapy in many Western cultures, especially in the U.S. and the U.K.. The authors surveyed 76 helping professionals to assess if the grief memoir is a genre with which they are familiar and whether they employ such narratives as an adjunct in their work with the bereaved. Most bibliotherapeutic studies focus either on self-help or affective literature. This study is unique in evaluating a life writing genre which promises to combine the therapeutic benefits of both. **Abstract:** <http://bit.ly/2MNEj5w>

The effect of early and systematic integration of palliative care in oncology on quality of life and healthcare use near the end of life: A randomised controlled trial

EUROPEAN JOURNAL OF CANCER, 2019;124(1):186-193. To the authors' knowledge, this is the first European study that examined the effect of early integration of palliative care (PC) in oncology on QoL near the end of life (EoL) of cancer patients. They found statistically significant beneficial effects in QoL at the EoL by providing patients with monthly semi-structured consultations with a specialised PC nurse, starting early in the disease trajectory and continuing until death. The plausible mechanism of the long-term benefit of early integrated PC versus on-demand PC could be related to the fact that patients and PC professionals have more time to build a relationship, to focus on coping with the progressive and worsening illness, to address decision-making in relation to cancer treatment and EoL care, and to enhance symptom assessment and management. Research has shown that adequate symptom management, effective communication, and a strong therapeutic bond contribute to quality EoL care. **Full text:** <http://bit.ly/2SKmAQm>



Cont.

Noted in Media Watch 2 September 2019 (#629, p.7):

- *PROGRESS IN PALLIATIVE CARE* | Online – 29 August 2019 – ‘**Integration of early supportive and palliative care in a patient’s journey with cancer.**’ Several trials suggest earlier provision of specialist palliative care (SPC) may increase quality of life, improve symptoms and facilitate considered end-of-life care planning. This appears beneficial; however, evidence is mixed about the effectiveness of early SPC and its potential benefits. Results, therefore, should be interpreted with caution. In reviewing the literature, it is clear that implementing early SPC is fraught with obstacles and requires increased resources and funding. Until the benefits and cost implications for such provision are better understood, it will not be accessible to all that may have potential to benefit. **Abstract:** <http://bit.ly/2zxn15F>

Noted in Media Watch 28 January 2019 (#599, p.11):

- *ONCOLOGY: RESEARCH & TREATMENT*, 2019;42:11-18. ‘**Early palliative care: Pro, but please be precise!**’ It is not a question of “if” palliative care (PC) should be integrated early into oncology, but “how.” General PC is defined as an approach that should be delivered by healthcare professionals regardless of their discipline. For this, routine symptom assessment, expertise concerning basic symptom management, and communication skills are basic requirements. “Early PC” must not be used synonymously with “early specialist PC” because much of the PC is delivered as basic oncology PC. For the integration of specialist PC, the identification of triggers is warranted in different institutions to facilitate a meaningful and effective cooperation. **Abstract (w. list of references):** <http://bit.ly/2QdAUPE>

The role of geriatric palliative care in hospitalized older adults

HOSPITAL PRACTICE | Online – 22 December 2019 – Geriatric palliative care (PC) requires integrating the disciplines of hospital medicine and PC in pursuit of delivering comprehensive, whole-person care to aging patients with serious illnesses. Older adults have unique PC needs compared to the general population, different prevalence and intensity of symptoms, more frequent neuropsychiatric challenges, increased social needs, distinct spiritual, religious, and cultural considerations, and complex medico-legal and ethical issues. Hospital-based PC interdisciplinary teams can take many forms and provide high-quality, goal-concordant care to older adults and their families. **Access article at:** <http://bit.ly/2ZAY8w>

Noted in Media Watch 23 December 2019 (#645, p.12):

- *ZEITSCHRIFT FÜR GERONTOLOGIE UND GERIATRIE* | Online – 11 December 2019 – ‘**Caring for frail older patients in the last phase of life: Challenges for general practitioners in the integration of geriatric and palliative care.**’ GPs see the care of frail older patients at the end of their lives through: 1) Growing number of older people; 2) Multimorbidity and complexity of the problem areas; 3) Integration of geriatric and palliative approaches; 4) The high average age of general practitioners and the lack of junior staff; and, 5) The problem of ensuring care in rural areas as a major challenge. The practical transition between geriatric and PC is considered by GPs to be fluid and there is a desire for more integration of both disciplines. **Abstract (w. list of references):** <http://bit.ly/2RWKJ5R>

N.B. German language article.

Noted in Media Watch 9 October 2017 (#533, p.16):

- *CURRENT ONCOLOGY REPORTS* | Online – 2 October 2017 – ‘**Using geriatric assessment strategies to lead end-of-life discussions.**’ End-of-life (EoL) discussions with geriatric oncology patients are a vital part of the comprehensive care of the senior adult patient. Patients and caregivers may have expectations that are not concordant with what is reasonably achievable if the patient is frail. Measuring baseline cognition, nutritional status, and physical function and discussing goals of care are all essential pieces of information that can be obtained through a comprehensive geriatric assessment ... crucial in developing EoL care plans that reflect both the patient’s health status and personal values. **Abstract (w. list of references):** <http://bit.ly/34jS173>

Cont.

Noted in Media Watch 17 April 2017 (#508, p.7):

- *CLINICS IN GERIATRIC MEDICINE* | Online – 6 April 2017 – ‘**Integrating quality palliative and end-of-life care into the geriatric assessment.**’ The comprehensive geriatric assessment is greatly enhanced by integration of ongoing palliative and end-of-life (EoL) care assessments. Discussions about advanced illness management and dying can improve outcomes. Common disease trajectories are evident that indicate a limited life expectancy and the need for palliative care. Common physiology and physical changes are evident, which can be used to improve palliative and EoL symptom management. Anticipation and management of the common physical, psychosocial and spiritual symptoms experienced at the EoL are vital to a quality death for older adults. **First page view:** <http://bit.ly/2Oh4SRH>

Physical restraining of nursing home residents in the last week of life: An epidemiological study in six European countries

INTERNATIONAL JOURNAL OF NURSING STUDIES | Online – 26 December 2019 – In all but one of the six countries studied nursing home staff reported that varying proportions of nursing home residents were restrained through limb and/or trunk restraints in the last week of life. The proportion of restrained residents was higher in Italy and Belgium, compared to Poland, Finland, England, and The Netherlands. Lack of or lower restraint use in several of the countries studied suggests that its reduction or elimination is a realistic and achievable aim. These data highlight a pressing need for national strategies aimed at preventing this practice. Clear guidelines for nursing home practice, alongside relevant legal frameworks, that explicitly discourage the use of physical restraints and suggest alternatives may be an effective component of such strategies. **Full text:** <http://bit.ly/39pkGKL>



Palliative care and end-of-life outcomes following high-risk surgery

JAMA SURGERY | Online – 2 January 2020 – In this cross-sectional study, receiving a palliative care (PC) consultation was associated with better overall care, communication, and support in the last month of life for patients who died within 90 days of high-risk surgery. Despite this, PC was not commonly used in a national cohort of patients undergoing high-risk operations. Providing PC for patients undergoing high-risk surgery may improve patient and family experiences at the end of life, per the results of this study. **Abstract:** <http://bit.ly/36oVrGr>

A national study of end-of-life care among older veterans with hearing and vision loss

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 30 December 2019 – Hearing and visual sensory loss is prevalent among older adults and may impact the quality of healthcare they receive. Few studies have examined sensory loss and end-of-life care (EoLC) quality. Medical record review of all veterans who died in an inpatient Veterans Affairs Medical Center between October 2012 and September 2017. Survey results included 42,428 individuals. Three indicators of high-quality EoLC were measured: 1) Palliative consultation in the last 90 days of life; 2) Death in a non-acute setting; and, 3) Contact with a chaplain. The Bereaved Family Survey (BFS) [used] reflects a global evaluation of quality of EoLC, pain and post-traumatic stress disorder management, and three sub-scales characterizing perceptions regarding communication, emotional and spiritual support, and information about death benefits in the last month of life. EoLC quality indicators and BFS outcomes for veterans with hearing loss were similar to those for veterans without hearing loss; however, the authors noted slightly lower scores for pain management and less satisfaction with communication. Veterans with vision loss were less likely to have received a palliative care consult or contact with a chaplain than those without vision loss. Although BFS respondents for veterans with vision loss were less likely than respondents for veterans without vision loss to report excellent overall care and satisfaction with emotional support, other outcomes did not differ. **Abstract:** <http://bit.ly/39uyUd9>

Cont.

Noted in Media Watch 14 January 2019 (#597, p.12):

- *JOURNAL OF PAIN & SYMPTOM MANAGEMENT* | Online – 7 January 2019 – ‘**Hearing loss: Effect on hospice and palliative care through the eyes of practitioners.**’ Discussions regarding values and goals of care are central to providing quality palliative care. An inability to hear during these sensitive discussions may significantly impair quality of care yet hearing loss (HL) is not formally addressed in these settings nor in programs designed to assist practitioners gain advanced communication skills. Of 510 survey respondents, 91% reported HL had impact on the quality of care provided, 88% noted encountering a situation where HL impaired communication with an older adult, and 22% of these provided a specific example. **Abstract (w. link to references):** <http://bit.ly/2srb95p>

N.B. Selected articles on the implications of hearing loss in the context of elder and EoLC are noted in this issue of Media Watch.

End of life in an acute hospital setting: A systematic review of families’ experience of spiritual care

JOURNAL OF CLINICAL NURSING | Online – 31 December 2019 – Although there is a widespread belief that the consideration of spiritual and religious needs is out-dated in the context of secularism, from a practical perspective patients and families appear to benefit from spiritual support at the end of life (EoL). Five main themes emerged: 1) Anticipating needs; 2) Honouring the family by honouring the patient; 3) Personal connection; 4) Lack of sensitivity; and, 5) Making space for religious and spiritual practices. Families experiencing EoL care in acute hospital settings may benefit from spiritual care. While this can also be considered as fundamental care, understanding this through the lenses of spiritual care allows for the incorporation of religious and spiritual practices that many seek at this time, irrespective of their faith perspectives. **Abstract:** <http://bit.ly/39zhqN9>

N.B. Selected articles on spirituality in the context of EoL care noted in 9 December 2019 issue of Media Watch (#643, p.14).

Hospice & Palliative Nurses Association position paper

The role of palliative care in donation for transplantation

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2019;21(6):E16-E18. Palliative care (PC) plays a role in the care of the donation after circulatory death donor to ensure attention to symptom management and family support. When donation is no longer an option, patient and family needs are respected and supported during the dying process. Post-death care should honor the patient’s and family’s cultural and spiritual beliefs, values, and practices. Healthcare professionals do not always feel sufficiently supported to provide the type of compassionate and open communication that they want to offer to families, particularly in organ and tissue donation. In addition to grief and moral distress, healthcare professionals often suffer from the stress of inadequate communication within the healthcare team itself. PC offers support to the staff who must change their role from life-sustaining directed care to organ protective care. The PC team achieves this through education, communication, and an emphasis on resilience and self-care. Within the critical care setting where donation occurs, PC providers may play an essential role in facilitating donation discussions through advance care planning conversations, providing expert symptom management for the patient, and supporting the family through the decision-making process, grief, and bereavement. Bereavement outcomes are more dependent on the family’s perceptions of the meaning of the death, the way they were treated by hospital personnel, the way the organ donation request was broached, and their own intrinsic worldview than by the fact of organ donation. PC may impact this perspective, as over the last decade, numerous publications identified PC as well-suited to support donors and their caregivers. Yet, the arena of organ donation remains a sensitive aspect of research, leading to insufficient literature of the optimal impact of PC. **First page view:** <http://bit.ly/2szmrUX>

N.B. Download/view the Association’s position paper at: <http://bit.ly/359LhZ5>

Interprofessional Master of Science in Palliative Care: On becoming a palliative care community specialist

JOURNAL OF PALLIATIVE MEDICINE | Online – 30 December 2019 – Palliative care (PC) is a limited resource in healthcare systems. Many providers develop a PC interest later in their careers when it is difficult to relocate and compete for a limited number of training positions. In communities without an academic tertiary medical center, interprofessional PC community specialists are poised to deliver high-quality accessible PC to patients/families with needs beyond what can be addressed by primary care providers. An interprofessional 36-credit Master of Science in Palliative Care (MSPC) provides evidence-based education to nurses, pharmacists, physicians, physician assistants, social workers, spiritual care providers, psychologists, counselors, and other allied health professionals. The predominantly online curriculum, designed and taught by an interprofessional faculty, focuses on interdisciplinary teamwork, communication skills, and practical application of biomedical and psycho-socio-cultural-spiritual-ethics content. The pedagogy is narrative based, emulating in-person clinical experiences, with patient cases progressing throughout the curriculum. The inaugural student cohort reports high levels of engagement and satisfaction, including mastery and synthesis of didactic and experiential content through case integration projects. Students who worked in PC/hospice settings have advanced in their professions; others have transitioned to PC work. The MSPC has capacity to meet projected PC workforce gaps. **Abstract:** <http://bit.ly/2rHNpJH>

Meaningful deaths: Home health workers' mediation of deaths at home

MEDICAL ANTHROPOLOGY | Online – 23 December 2019 – After several generations in the U.S. in which medicalized deaths have become normal, more people are seeking to die at home. However, home deaths lead to emotional uncertainty and practical confusion, in which kin lack a cultural script. In this article the author draws on interviews with patients' kin and their African immigrant home health workers, and show that the care workers helped create a more meaningful death through their knowledge of death, familiarity with the physical processes of death, and their presence, which they used to create pathways for their patients and their kin. **Abstract:** <http://bit.ly/37nlzSq>

Noted in Media Watch 16 December 2019 (#644, p.2):

- *THE NEW YORK TIMES* | Online – 11 December 2019 – ‘**More Americans are dying at home than in hospitals.**’ For the first time over a half century, more people in the U.S. are dying at home than in hospitals, a remarkable turnabout in Americans’ view of a so-called “good death.” In 2017, 29.8% of deaths by natural causes occurred in hospitals, and 30.7% at home, researchers report...¹ The gap may be small, but it had been narrowing for years, and the researchers believe dying at home will continue to become more common. The last time Americans died at home at the current rate was the middle of the last century, according Dr. Haider J. Warraich, a cardiologist at the Veterans Affairs Boston Healthcare System and a co-author of the new research. <https://nyti.ms/38B6qOP>

1. ‘Changes in the place of death in the U.S.,’ *New England Journal of Medicine*, 2019;381(24):2369-2370.
Access article at: <http://bit.ly/35fjbfL>

Reducing time in acute hospitals: A stepped-wedge randomised control trial of a specialist palliative care intervention in residential care homes

PALLIATIVE MEDICINE | Online – 2 January 2020 – Needs Rounds offer a robust proactive approach to reducing length of stay in hospital and number of hospitalisations, by focusing on those with greatest symptom burden, providing specialist clinical care, education and anticipatory planning, including access to medications needed at end of life (EoL). Preventing inappropriate admissions to acute care, and reducing length of stay where possible, fits with quality clinical practice goals for care home residents, for example, facilitating people to die in their preferred place of the care home, rather than in hospital. This model focuses on people with the most complex care needs, who by virtue of their residence in care are likely to be approaching EoL. Consequently, this intervention is better tailored to care home residents

Cont.

than other interventions which focus on care coordination or primary palliative care (PC). This intervention is also flexible to the changing needs of care homes and their staff. The degree of focus on different components of Needs Rounds, such as staff education and the determination of when specialist clinical input is required, is dynamic allowing responsiveness to local context. This is of particular utility due to the known high-turnover of care home staff, the related difficulties in maintaining care practices, and jurisdictional differences in determining the role and availability of specialist PC in care homes. **Full text:** <http://bit.ly/35fM4rs>

The impact of palliative care consults on deprescribing in palliative cancer patients

SUPPORTIVE CARE IN CANCER | Online – 23 December 2019 – The transition from active cancer treatment to palliative care (PC) often results in a shift in drug risk-benefit assessment which requires the deprescribing of various medications. Deprescribing in palliative cancer patients can benefit patients by reducing their pill burden, decrease potential side effects, and potentially decrease healthcare costs. In addition, a change in patients' goals-of-care (GoC) necessitates the alteration of drug therapy which includes both deprescribing and the addition of medications intended to improve quality of life. Depending on a patient's GoC, a medication can be considered as inappropriate. This study shows the positive impact a PC consult has on deprescribing and reveals the importance of using guidelines for deprescribing in palliative cancer patients. **Abstract (w. list of references):** <http://bit.ly/2F1yU6L>

N.B. Selected articles on deprescribing in PC noted in 28 October 2019 issue of Media Watch (#637, p.7).

Brain death criteria: Medical dogma and outliers

YALE JOURNAL OF BIOLOGY & MEDICINE, 2019;92(4):751-755. The diagnosis of brain death (BD) is legally and medically accepted. Recently, several high-profile cases have led to discussions regarding the integrity of current criteria, and many physiologic problems have been identified to support the necessity for their reevaluation. These include a global variability of the criteria, the suggestion of a clinical "hierarchy," and the resultant approximation of BD. Further ambiguity has been exposed through case reports of reversible BD, and an inconsistent understanding from physicians who are viewed as experts in this domain. Meeting BD criteria clearly does not equate to a physiologic "death" of the brain, and a greater community perspective should be considered as the dialogue moves forward. Advanced technology and medical practice continue to present societies with similar issues that prompted the sentinel BD dialogue in 1968: how should we ethically and humanely navigate the realities of patients with little to no discernible brain function. The current BD guidelines are the result of several ambitious and independent processes that sought to address these challenges. They are however, flawed, self-contradictory, and are now beginning to be challenged. The language in current guidelines should reflect these flaws by eliminating all references to whole brain death and adequately addressing their limitations. Recognizing these limitations and opening up a public dialogue should improve trust to our institutions, rather than hiding behind medical dogma. **Full text:** <http://bit.ly/2SA19RV>

N.B. The current issue of the *Yale Journal of Biology & Medicine* explores the major advances and unresolved questions about death. **Journal contents page:** <http://bit.ly/36XoEs2>

Noted in Media Watch 2 December 2019 (#642, p.10):

- *THE LINACRE QUARTERLY*, 2019;86(4):268-270. '**Exploring the life death divide, questions remain long after the Harvard Criteria.**' For modern medicine, the development of neurological criteria for declaring death is a milestone event. The development of life support systems that could sustain organ function in the face of catastrophic brain injury occasioned both the desire and the need to be able to assess death in different ways than in the past. Questions arose about when and how such support might be discontinued, in large part because traditional ideas about death involved cessation of the very organ function that could now be sustained. The question began to be asked: where is the line between life and death in light of these new technologies? **Full text:** <http://bit.ly/2DmvUB3>

N.B. The focus of the current issue of *The Linacre Quarterly* is on current understanding and questions regarding brain death. **Journal contents page:** <http://bit.ly/34uahe1>

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *BMC MEDICAL ETHICS* | Online – 27 December 2019 – ‘**Assessing attitudes towards medical assisted dying in Canadian family medicine residents: A cross-sectional study.**’ Attitudes towards physician hastened death (PHD) in general and the specific provision of medical assistance in dying (MAiD) are unknown among Canadian residents. Overall, 247 residents from 6 family medicine training programs in Canada participated in this study. While residents were most willing to participate in treatment withdrawal, active participation in PHD and MAiD ... were less acceptable. Logistic regressions identified religion as a consistent and significant factor impacting residents’ willingness to participate in PHD and MAiD. Residents who were not strictly practicing a religion were more likely to be willing to participate in PHD and MAiD. Increased clinical exposure to death and dying crudely correlated with increased willingness to participate in PHD and MAiD, but when examined in multivariable models, only a few activities ... had a statistically significant association. Other significant factors included the residents’ sex and location of training. **Full text:** <http://bit.ly/2ZvSEsz>

[Media Watch: Editorial Practice](#)

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

[Distribution](#)

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

[Links to Sources](#)

1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.
2. Links are checked and confirmed as active before each edition of the weekly report is distributed.
3. Links often remain active, however, for only a limited period of time.
4. Access to a complete article, in some cases, may require a subscription or one-time charge.
5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

[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



INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://bit.ly/2OVQyP3>

[Scroll down to 'Media Watch: The Homeless']

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://bit.ly/2ThijkC>

PALLIATIVE CARE NETWORK: <http://bit.ly/37x69uD>

PALLIMED: <http://bit.ly/2ResswM>

[Scroll down to 'Media Watch by Barry Ashpole'; also 'Media Watch: Behind the Scenes' at: <http://bit.ly/2MwRRAU>]

Australia

PALLIATIVE CARE RESEARCH NETWORK: <http://bit.ly/2E1e6LX>

[Click on e-News (November 2019); scroll down to 'Useful Resources in Palliative Care Research']

Canada



CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: <http://bit.ly/2Dz9du3>

[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | HPC Consultation Services (Waterloo Region, Wellington County): <http://bit.ly/2TboKFX>

Europe



EUROPEAN ASSOCIATION FOR PALLIATIVE CARE (BLOG): <http://bit.ly/2XC24jA>

HUNGARY | Magyar Hospice Alapítvány: <http://bit.ly/2RgTvYr>

U.K. | Omega, the National Association for End-of-Life Care: <http://bit.ly/2MxVir1>

South America

Academia Nacional de Cuidados Paliativos (Brazil): <http://bit.ly/2G2ISGr>

Barry R. Ashpole, Ontario CANADA

e-mail: barryashpole@bell.net