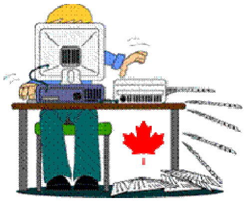
Media Watch...

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.*

11 September 2017 Edition | Issue #529



Compiled & Annotated by Barry R. Ashpole

The Illness experience: Scroll down to Specialist Publications and 'Honoring the voices of bereaved caregivers: A meta-summary of qualitative research' (p.6), in *BMC Palliative Care*.

Canada

Ontario should better coordinate health-care patient information

ONTARIO | *The Ottawa Citizen* – 8 September 2017 – Today in Ontario and beyond the confines of its hospitals, patient information is often fragmented and siloed. Clinicians often lack the means to share and access complete information with other clinicians when they provide care and care planning for their patients. This often leaves a patient having to answer similar questions raised by multiple clinicians, and unnecessarily repeat procedures, while increasing the potential for medication errors. Integration and sharing of patient information is fundamental for coordinated care. For care to be coordinated, it needs to be wrapped around the patient. Improved care coordination has been shown to have positive impacts across the system. Evidence shows that, in addition to technology, face-to-face and home visits significantly improve outcomes for these patients. Furthermore, hospital readmission rates are reduced in a range of environments and settings. Another highly relevant area for care coordination is planning for the end-of-life (EoL). Dr. Jocelyn Charles, who has been appointed to physician adviser, primary care strategy, with the Toronto Central Local Health Integration Network, discussed how a fully integrated model of care coordination changes the way health-care providers interact with patients, colleagues and families during the trying EoL time. https://goo.gl/ULv8Co

Specialist Publications

'Acute care hospitalization near the end of life for cancer patients who die in hospital in Canada' (p.7), in *Current Oncology*.

'Experiences of Canadian oncologists with difficult patient deaths and coping strategies used' (p.7), in *Current Oncology*.

'A test for freedom of conscience under the Canadian Charter of Rights & Freedoms: Regulating and litigating conscientious refusals in health care' (p.11), in *McGill Journal of Law & Health.*

U.S.A.

Shedding new light on hospice care: No need to wait for the "brink of death"

KAISER HEALTH NEWS | Online – 7 September 2017 – A few weeks ago, Kathy Brandt's 86-year-old mother was hospitalized in Florida after a fall. After rushing to her side, Brandt asked for a consult with a palliative care nurse. "I wanted someone to make sure my mother was on the right medications," Brandt said. For all her expertise – Brandt advises end-of-life organizations across the country – she was taken aback when the nurse suggested hospice care for her mother, who has advanced chronic obstructive pulmonary disease, kidney disease and a rapid, irregular heartbeat. "I was like – really?" Brandt remembered saying, struggling with shock. It's a common reaction. Although hospices now serve more than 1.4 million people a year, this specialized type of care, meant for people with six months or less to live, continues to evoke resistance, fear and misunderstanding. The biggest misperception about hospice is that it's "brink-of-death care." https://goo.gl/enUdvj

Specialist Publications

'Compassionate release policy reform: Physicians as advocates for human dignity' (p.5), in *AMA Journal of Ethics.*

'Palliative care professional development for critical care nurses: A multicenter program' (p.4), in *American Journal of Critical Care*.

Doctors want to give their cancer patients every chance. But are they pushing off hard talks too long?

PUBLIC BROADCASTING SERVICE | Newshour – 2 September 2017 – A new generation of immune-boosting therapies has been hailed as nothing short of revolutionary, shrinking tumors and extending lives. When late-stage cancer patients run out of other options, some doctors are increasingly nudging them to give immunotherapy a try. But that advice is now coming with unintended consequences. Doctors who counsel immunotherapy, experts say, are postponing conversations about palliative care (PC) and end-of-life wishes with their patients – sometimes, until it's too late. PC and oncology teams have long been wary of each another. For many oncologists, PC teams are the specialists to call in only when curative treatments have been exhausted. For many PC specialists, oncologists are the doctors who prescribe treatments without regard to quality-of-life considerations. But the new collision between immunotherapy and PC experts comes at an inopportune moment for health care providers, who have in recent years promoted PC as a way to increase patient satisfaction while reducing costs associated with hospitalizations and emergency room visits. https://goo.gl/1oJ2W9

Noted in Media Watch 21 August 2017 (#526, p.13):

- *JOURNAL OF ONCOLOGY PRACTICE* | Online – 16 August 2017 – **'Palliative care in special settings of cancer care.'** Within oncology, surgical, radiation, medical, gynecologic, malignant hematologic, transplantation, and pediatric fields are distinct tribes with distinctive rites and rituals of usual behavior that are carried out in special settings. Successful integration of palliative care requires a keen and unabashed recognition of this. https://goo.gl/1yAUws

N.B. The integration of palliative care into standard oncology care is the focus of several articles published recently in the *Journal of Oncology Practice* and noted in the 28 August 2017 issue of Media Watch (#527, beginning on p.11).

Media Watch Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing beginning on p.13.

Assisted (or facilitated) death

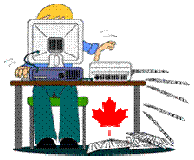
Representative sample of recent news media coverage:

- COURTHOUSE NEWS SERVICE – 8 September 2017 – **'New York's top court keeps assisted suicide a crime.'** Two terminally ill plaintiffs who sued to decriminalize physician-assisted suicide in New York lost painful battles with Lou Gehrig's disease and AIDS last year. On Thursday, the lawsuit they pursued up until the end died too. New York's Court of Appeals ...found that any relaxation of New York's centuries-old prohibitions would have to come from Albany. https://goo.gl/yTo8GC

- WASHINGTON DC | *The Washington Examiner* – 3 September 2017 – **'A momentum shift against assisted suicide.'** Twenty-three states have rejected bills attempting to legalize assisted suicide since the beginning of 2017, and these bills are now considered dead for the remainder of the year. Why such unusual bipartisan consensus? The states that defeated these bills to legalize or expand assisted suicide run the gamut politically, from New York and Rhode Island to Utah and Indiana. Such bills were defeated by votes in the legislature, died from inaction, stalled in committee or were completely withdrawn. A circuit court in Hawaii dismissed a lawsuit which asked the court to resolve that the criminal laws in the state should not apply to assisted suicide. And there are four additional states – Pennsylvania, Wisconsin, Minnesota and Michigan – that are unlikely to act on similar measures this fall. Another indication that momentum is shifting in opposition to the expansion of this practice is states like Alabama and Ohio recently enacted laws to strengthen prohibition of assisted suicide. And a congressional committee passed an amendment to their appropriations bill to repeal the new Washington DC law legalizing assisted suicide. https://goo.gl/zSh6q1

Specialist Publications

'Changing attitudes toward euthanasia and suicide for terminally ill persons, 1977 to 2016: An age-period-cohort analysis' (p.12), in *Omega – Journal of Death & Dying.*



Barry R. Ashpole

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

PALLIMED
A HOSPICE & PALLIATIVE MEDICINE BLOG

Media Watch: Behind the Scenes
http://goo.gl/XDjHxz

Specialist Publications

Embedding a palliative approach in nursing care delivery: An integrated knowledge synthesis

ADVANCES IN NURSING SCIENCE, 2017; 40(3):263-279. Findings from this study inform the ways in which nursing can have a significant role in enhancing care for this population [i.e., persons who have life-limiting conditions throughout their illness trajectories] through a palliative approach (PA). Based upon these findings, a 3-faceted approach is necessary. First, there needs to be a concerted focus on knowledge translation regarding the fundamental values and tenets that constitute a PA. A PA is ultimately a person-centered approach to care. Therefore, knowledge translation efforts toward a PA will be fulfilling an important mandate within health care internationally. Second, there needs to be a focus on empowering those in the care delivery team whose contributions have been less visible. In particular, the unregulated workforce are essential partners in care delivery to this population. These important partners must be part of the integration of a team-based approach and necessary practice supports. Third, the scaffolding of practice supports is critical to this envisioned shift. Nurses require supports that facilitate high-quality care and communication such as education, clinical pathways, assessment instruments, and documentation mechanisms. However, these supports can be implemented only in concert with fundamental values that are in keeping with a PA. We need to be cautious about the implementation of these supports without due attention to shifts in philosophy and empowerment. Important lessons were learned from the implementation of the Liverpool Care Pathway about the importance of the underlying philosophy and values. **Full text:** https://goo.gl/Rg5dT3

The process of death and dying: Challenges in nursing care for patients and family members

NORTHEAST NETWORK NURSING JOURNAL, 2017;18(4):528-535. Among the actions and interactions performed in caring for patients and their families in the process of death and dying, we can point out the way nurses respond to the challenges of their professional performance. Faced with a weakness in training on the theme, they seek to build a bond with the patient and the family in order to guarantee care humanization and comprehensiveness, supporting and respecting their mourning process based on empathy and using spiritual beliefs and the sharing of experiences with peers as coping strategies. **Abstract:** https://goo.gl/SYrYcU

N.B. To access **full text** click on pdf icon.

Related

- *AMERICAN JOURNAL OF CRITICAL CARE*, 2017;26(5):361-371. **'Palliative care professional development for critical care nurses: A multicenter program.'** The program consisted of 8-hour communication workshops for bedside nurses and structured rounds in ICUs, where nurse leaders coached bedside nurses in identifying and addressing PC needs. Primary outcomes were nurses' ratings of their PC communication skills in surveys, and nurses' identification of PC needs during coaching rounds. Each center held at least 6 workshops, training 428 bedside nurses. Nurses rated their skill level higher after the workshop for 15 tasks (e.g., responding to family distress, ensuring families understand information in family meetings...). Coaching rounds in each ICU took a mean of 3 hours per month. For 82% of 1,110 patients discussed in rounds, bedside nurses identified PC needs and created plans to address them. **Abstract:** https://goo.gl/Wo2NHg

  N.B. Additional articles on palliative care in the intensive care unit are noted in the 17 July 2017 issue of Media Watch (#521, p.12).

- *NURSING STANDARD* | Online – 30 August 2017 – **'Ensuring dignity in death: A nurse-led training initiative has given staff in a hostel for homeless people the skills to care for clients at the end of life.'** Homeless people are dying in unsupported and unacceptable situations with inadequate access to palliative care, a recent study found. **Access options:** https://goo.gl/UyM4Ka

  N.B. Additional articles on end-of-life care for the homeless noted in the 14 August 2017 issue of Media Watch (#525, p.14).

Compassionate release policy reform: Physicians as advocates for human dignity

AMA JOURNAL OF ETHICS, 2017;19(9):854-861. Compassionate release policies are designed in recognition of the fact that an appropriate level of care for patients with severe or debilitating illnesses is difficult, and sometimes impossible, to achieve in the correctional setting. For instance, the community standard for end-of-life care is to offer patients hospice; however, prison hospices are available only at 69 of 1,719 state correctional facilities, and they often require patients to move farther away from family or friends at a time when maintaining social connections is a core component of quality care. Prison hospice programs are costly, straining state allocations for correctional health services, which cannot be billed to Medicare and Medicaid. Consider the film ‘Prison Terminal: The Last Days of Private Jack Hall,’[1] which depicts a prison hospice program that was made possible by fundraising rather than budgetary allocation. The film highlights comfort measures provided by incarcerated persons employed to help the patient but depicts relatively little in the way of professional hospice nursing and palliative care. In fact, a few days before his death, the patient is shackled, put in an orange jumpsuit, and taken by ambulance to the nearest emergency room, where he can receive appropriate medical care. Cost and logistical limitations make it very difficult to provide standard-of-care hospice care in prisons, threatening the dignity of the seriously ill and offering a strong rationale for compassionate release policies. Although there are several reasons why the medical community should advocate for evidence based compassionate release policies – including the high cost of care for these patients – the authors focus in this paper on the ethical value of human dignity. **Full text:** https://goo.gl/kRyCRG

Palliative Care Network Community

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of selected articles, reports, etc., noted in past issues of the weekly report (updated 31 July 2017) can be downloaded/viewed at: http://goo.gl/ZpEJyQ

[1] ‘Prison Terminal: The Last Days of Private Jack Hall’: https://goo.gl/oUDVT6

N.B. The focus of this issue of the American Medical Association publication is incarceration and correctional health care. Journal contents page: https://goo.gl/vWa9e1

Sexuality, intimacy and palliative care

AUSTRALIAN HOSPITAL & HEALTHCARE BULLETIN | Online – 1 September 2017 – A groundbreaking program at Sydney’s Neringah Hospital is now addressing this concern for people coming to the end of their life. At Neringah, a 19-bed palliative care (PC) hospital, patients and staff are encouraged to normalise topics around sex and sexual desire. “Sexuality and dying are considered taboo subjects, and most people feel that people in this stage of their lives are too ill to think about sex,” said Brigitte Karle, clinical nurse educator with HammondCare. “But our PC staff – and our patients – recognise that sexuality is part of the holistic care of patients, and this has resulted in the ‘Let’s Talk About It’ program. We need to make it easier for patients, their partners and staff to feel that they can have the conversation without being uncomfortable,” she said. “Through our research we have identified that patients would like staff to initiate the conversation, and we have implemented a system where staff feel confident to recognise cues to take the appropriate action to provide ‘private couple time.’ We also identified a need for staff to have additional training and education so they feel more comfortable about the issue.” Karle said Neringah’s unique set-up, which includes private rooms, allowed patients to have intimate private relationships with their partners that might not be available in other hospitals. **Full text:** https://goo.gl/desUWQ

N.B. Additional articles on sexuality and intimacy in the context of living with a life-limiting or terminal illness are noted in Media Watch 13 Mar 2017 (#503, pp.4,16).

What are families most grateful for after receiving palliative care? Content analysis of written documents received: A chance to improve the quality of care

BMC PALLIATIVE CARE | Online – 6 September 2017 – Knowing family carers' perception and understanding their experiences is a chance to enhance how to be helpful to patients and family members, and allows palliative care professionals to identify positive aspects of their care in order to improve the assistance provided to patients and family carers. Despite the sadness of their loss, comments from family carers provide valuable input about their points of view of the scope of care. Family carers highlight the importance of key aspects that require a close relationship between health professionals and themselves, suggesting that this component or aspect could be used as a quality indicators of care. Three different content categories emerged from the authors' analysis: 1) Recognition of the care received and the value of particular aspects of care within recognised difficult situations included aspects such as kindness, listening, attention to the family, empathy, closeness, affection and the therapeutic relationships established; 2) Family recognition of the achievements of the PC team indicated as relief from suffering for the patient and family, opportunity of dying at home, help in facing difficult situations, improvement in quality of life and wellbeing, and feeling of serenity during bereavement; and, 3) Messages of support related to the need of resources provided. The relational component emerges as an underlying key aspect of family carers' experience with PC home service. **Full text:** https://goo.gl/ywTHCF

Honoring the voices of bereaved caregivers: A meta-summary of qualitative research

BMC PALLIATIVE CARE | Online – 6 September 2017 – Family caregiving in the context of advanced disease in particular, can be physically and emotionally taxing. Caregivers can subsequently face bereavement exhausted with few supports, limited resources and a significant proportion will develop negative psychological and social outcomes. Although some research has attended to the bereavement experiences of family caregivers who had cared for a person requiring palliative care (PC), a comprehensive qualitative understanding of the impact of caregiving on bereavement has not been articulated. The purpose of this study was ... to explore the experiences of bereaved family caregivers of people who received PC services, regardless of their underlying disease. The sample consisted of 47 qualitative studies. A total of 15 themes emerged. In descending order of frequency, the 15 themes were: the individual emotions of serenity, sadness, guilt, uncertainty, trauma, escape, and anger; post-loss experiences that helped the caregiver in bereavement; post-loss experiences that hindered; practical life changes; caregiver role identity; pre-loss experiences that helped; pre-loss experiences that hindered; caregiver context; and a need for different kinds of supports. Three key findings emerged from the themes: 1) Many different aspects of the caregiving experience impact the bereavement experience; 2) Every bereavement experience is unique; and, 3) A variety of supports must be developed and made available to caregivers to meet these unique needs. **Full text:** https://goo.gl/HW3VL1

Related

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 8 September 2017 – '**Cancer caregivers' preparedness for loss and bereavement outcomes.**' Nearly half [of study participants] reported they were not emotionally prepared, and 35% were not prepared for the practical challenges associated with the loss. Although attributes such as depression, anxiety, competence in daily activities, and financial adequacy were associated with both preparedness and bereavement outcomes, regression analyses revealed that preparedness remained the strongest predictor in all models. **Abstract:** https://goo.gl/XYpV1J

Can digital stories go where palliative care research has never gone before? A descriptive qualitative study exploring the application of an emerging public health research method in an indigenous palliative care context

BMC PALLIATIVE CARE – 4 September 2017 – The many disparities amongst countries worldwide means people face different palliative care and end-of-life scenarios. As a result, a diversity of responses are called for, which means new research methods are required to explore ways in which care might be most effectively delivered. Digital storytelling is one such method worthy of consideration. **Full text:** https://goo.gl/XQH1U2

End-of-life care in U.S.

Cardiac palliative medicine

CURRENT HEART FAILURE REPORTS | Online – 6 September 2017 – Heart failure is an illness with high morbidity and mortality that affects 5.7 million Americans. As advanced heart therapies become more prevalent care for patients and families is becoming more complex. The American Heart Association has released a policy statement recommending continuous, high-quality access to palliative care (PC) for all patients with heart failure, and the Center for Medicare Services requires PC involvement in mechanical circulatory support teams. The National Quality Forum developed eight domains of PC that are required for high-quality delivery of comprehensive PC. This article assesses each domain and how it pertains to evolving care of patients with advanced heart failure. **Abstract:** https://goo.gl/BeWC5W

> **N.B.** Additional articles on end-of-life care for people living with heart failure are noted in the 28 August 2017 issue of Media Watch (#527, p.9).

Acute care hospitalization near the end of life for cancer patients who die in hospital in Canada

CURRENT ONCOLOGY, 2017;24(4):256-261. This study provides information about the current landscape of acute care hospital use by cancer patients near the end of life (EoL) across Canada, examining variation in use by province. These data will add to the existing body of research about EoL care for patients with cancer and offer new findings about interprovincial variation in the management of EoL care. An international comparative study of hospital use during the last 30 days of life found that, of 7 countries, Canada fell into the middle range for hospital use, including number of hospital days at the EoL for patients dying from cancer. Patients spent 7.7 days in hospital at the EoL in Canada. The number of hospital days was higher in Belgium (10.6 days) and lower in Germany and England (7.4 days). It is possible that the cost of a hospital stay influences the need to find alternatives to hospitalization such as home or hospice. As reported in that study, the *per diem* cost for a hospital stay is relatively high in the U.S., which could be one factor influencing hospital use. A systematic review of the evidence for effective palliative care (PC) revealed that jurisdictions with earlier PC intervention had higher hospice enrolment, fewer hospital admissions, and fewer days spent in hospital near the EoL. **Full text:** https://goo.gl/T5dRDi

Related

- *CURRENT ONCOLOGY*, 2017;24(4):e277-e284. **'Experiences of Canadian oncologists with difficult patient deaths and coping strategies used.'** The authors sample of Canadian oncologists listed a number of interpersonal and structural factors that make it particularly challenging for them to cope with patient death. Early integration of palliative care into the treatment trajectory might help to ameliorate some of those factors and, in the process, might improve quality of life for oncologists who have frequent exposure to patient death. Moreover, apart from the importance of peer support, Canadian oncologists listed a broad variety of coping strategies used in responding to patient death. Given that variety, no single intervention will be suitable for all oncologists, and institutions that want to help their staff cope with the emotional difficulty of patient loss should offer a variety of optional interventions, thus maximizing the likelihood that oncologists will participate in the interventions and that the interventions themselves will be useful for the health care staff. **Full text:** https://goo.gl/d8n2zW

14 October 2017

Universal health coverage and palliative care – Don't leave those suffering behind

https://goo.gl/diYn7i

Reflections on hosting a series of death cafes in an National Health Service context

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(4): 153-155. The death cafe movement is a social franchise set up in the U.K. in 2011 by Jon Underwood and Sue Barsky Reid. It is a space where people, often strangers, come together to share food, drink tea, and talk about death. The movement was inspired by the work of Swiss sociologist Bernard Crettaz, who set up the first "café mortel" in 2004, with the aim of addressing the social taboo of talking about death and dying. Since the death cafe movement was established, 5,300 cafes have been held in more than 50 countries across Europe, North America and Australasia. The intention of a Death Cafe is to help people make the most of their finite lives, which is facilitated by group-directed discussion with no agenda. They are not therapy or support groups, though those taking part may experience the conversations that occur as therapeutic. Cafes are often aimed at the general public although, as their popularity has risen, events have been set up with specific groups and communities in mind. Likewise, our cafes were specifically aimed at people working in healthcare and National Health Service settings. In this way, our initiative was to make available these powerful and important spaces within professional health contexts to enable difficult conversations about death and dying, in recognition of the fact that they are central to both our personal and professional lives.

Access to the *European Journal of Palliative Care* requires a sub-scription to the publication. July/ August issue contents page: https://goo.gl/TWrbfn

Palliative care for slum populations: A case from Bangladesh

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(4):156-160. There are enormous challenges in running a slum-based community palliative care (PC) project of this type, characterised by a highly mobile population, informal power structures and high levels of uncertainty. Yet it is apparent from the evaluation that the project has achieved considerable success within a year. The clients are highly satisfied with the services they have received and appear to have benefited physically, socially, psychologically and spiritually – reflecting the component parts of the project. The community volunteers who were chased away by slum dwellers at the beginning of the project are now made welcome in people's houses. The objectives of PC are now known and appreciated by the community. Globally, there are very few examples of community oriented end-of-life care in resource poor settings such as this. It is widely argued that perhaps the most refined version of the model is the Neighbourhood Networks in Palliative Care (NNPC) in Kerala, India. The NNPC is an attempt to facilitate a sustainable, community-led service capable of providing PC to all those in need, with limited resources. Given the fact that almost all the available PC services in Bangladesh have taken institution-based approaches following Western models, this community-based initiative in the slum may have much to teach us.

Palliative care in Serbia: Parents' point of view

EUROPEAN JOURNAL OF PALLIATIVE CARE, 2017;24(4):186-190. Palliative care (PC) is a new and evolving field of medicine in Serbia, and paediatric PC is in a very early phase of formal development. For children in Serbia with life-limiting conditions, there are neither in-patient units nor co-ordinated services for PC. An open-ended survey of 20 parents of children with cancer receiving secondary oncologic treatment revealed that only one in four parents have a partial understanding of PC. Parents familiar with PC associate it with fear, sadness, helplessness and discomfort but also with the expectation of help during difficult times. Two-thirds of parents said the medical team was readily available, whereas one-third felt their medical team was not available to them. Four-out-of-five parents felt that the psychologist was the easiest member of the healthcare team to talk with.

Cont.

Noted in Media Watch 26 January 2015 (#394, p.10):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2015;22(1):30-33. '**Palliative care development in Serbia, five years after the national strategy.'** In 2009, the Serbian Ministry of Health adopted a national palliative care (PC) strategy, setting out the vision of a comprehensive and modern system of PC services across Serbia. From March 2011 to November 2014, a European Union-funded project was conducted to implement the strategy through the provision of technical assistance and the application of European and international standards. Major advances have been achieved in education, services, policies and legislation, as a result of which the status of PC in Serbia has progressed from localised provision to preliminary integration. However, there is further to go in order to ensure that PC is fully accessible to all who need it.

  N.B. November/December 2014 journal contents page: https://goo.gl/a3eG7Y

What is hospice, really?

IN-TRAINING (Albany Medical College, Albany, New York) | Online – 4 September 2017 – To physicians, hospice frequently symbolizes defeat. Referring a patient to hospice care can feel like admitting that disease has defeated years of training. In medical school, we are trained that the role of the doctor is to fight the disease and find the cure. As we battle against bacteria and cancerous cells, and it is easy to forget that despite it all, we are still dying. It is, therefore, comforting to know that there are healthcare providers who specialize in guiding people through the process of dying. As physicians, we need to reframe our thinking about hospice care from an admission of defeat to the inevitable conclusion of every person's path. Hospice can play a similar role as that of a pediatrician: documenting milestones and charting a progression with anticipatory guidance for what will come next. **Full text:** https://goo.gl/64cAfX

End-of-life care: Consensus statement by Indian Academy of Pediatrics

INDIAN PEDIATRICS | Online – 24 August 2017 – A National Consultative meet was organized by Indian Medico- Legal & Ethics Association and the Medico-legal group of Indian Academy of Pediatrics to formulate the guidelines on do not resuscitate (DNR) and end-of-life (EoL) support. The following recommendations emerged: 1) DNR or EoL care should not be activated till consensus is achieved between treating team and next of kin; 2) Consensus within health care team (including nurses) needs to be achieved before discussion with family members; 3) Discussion should involve the family members – next of kin and other persons who can influence decisions; 4) If family members want to include their family physician or a prominent person from community, it should be encouraged. Similarly if family members want a particular member of treating team, he/she should be included; 5) Treating doctors should have all the facts of the case including investigations available with them before discussion; 6) Unit in-charge or treating doctor should be responsible for achieving consensus and should initiate the discussion; 7) After presenting the facts of the cases, family members should be encouraged to ask questions and clear doubts (if any); 8) At the end of discussion, a summary of the discussion should be prepared and signed by the next of kin and the unit in-charge or treating doctors; 9) DNR orders should be reviewed in the event of unexpected improvement or on request of next of kin. Same should be documented; 10) DNR orders remain valid during transport. **Abstract:** https://goo.gl/deLn2V

The spiritual nature of uncertainty among hospice patients

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2017;19(5):480-486. People with protracted and life-limiting illness engage in end-of-life (EoL) transitions as they prepare for death. The EoL is a time of mystery that elicits uncertainties in the form of questions, worries, and doubts. If not managed properly, uncertainties can contribute to emotional distress and feelings of lost control. Currently, uncertainty occurring at the EoL is under researched. Study participants were asked to describe the uncertainties that they had while they were dying. Interestingly, most of the stories about uncertainty were spiritual in nature. An overall theme of "uncertainty as a bridge" emerged from the data as the way uncertainties affected their dying. Two sub-themes of "uncertainties about dying" and "uncertainties about important relationships" also emerge as the areas of greatest concern for participants. **Abstract:** https://goo.gl/VbvXxp

Unpacking the meaning of “transitional palliative care”: From the lens of the older persons and their carers

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2017;19(5):487-497. This article synthesizes literature for better understanding of the concept of transitional palliative care (TPC) within the context of older people moving from hospital to the community with life-limiting conditions and palliative care (PC) needs. The constructs gleaned from the synthesis connote that transitional care is more than only an act of transfer as older adults experience multiple transitions in our health care environment. It is a process of adjustment and adaptation for older adults to accommodate the changes as a result of the illness experience. The transition from cure to PC is one of the ongoing tensions because our health care system favors goals directed toward cure instead of comfort. The concept of a shift to palliation is also not enabled in a structure that a “one-size-fits-all” notion applies. The authors argue that current forms of TPC ignore influences of multifaceted health and social factors, which impact choices of older persons and their families. **Abstract:** https://goo.gl/2Qc4wP

A digital pain and analgesic diary for home hospice care

JOURNAL OF PALLIATIVE CARE | Online – 4 September 2017 – Informal hospice caregivers play a key role in managing patients’ pain at home, but lack of adherence to doctor-prescribed analgesic regimens and medication errors are significant barriers to truly effective pain management. A digital pain diary may improve caregiver management of pain at home; however, most digital pain tools available today were developed without input from patients or caregivers. Accordingly, the purpose of this study was to develop a digital pain application: 1) For hospice caregivers to record patient pain and analgesic use; and, 2) For nurses to monitor administration of analgesics by caregivers. Using advisory group methods, nurse case managers, and informal caregivers helped us to convert a paper-based pain and analgesic diary into a digital format – the e-PAIN Reporter – and to refine the application. The e-PAIN Reporter provides information on patient pain assessment and pain management and reports to nurses in real time. Further testing is now needed to determine: 1) The feasibility of using the e-PAIN Reporter; and, 2) Its effective-ness in improving pain management for hospice patients. **Abstract:** https://goo.gl/XAqhgh

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 6 September 2017 – **‘Pain management concerns from the hospice family caregivers’ perspective.’** This study confirmed that hospice family caregivers face a variety of challenges: caregiver-centric issues, caregiver’s medication skills and knowledge, communication and teamwork, organizational skill, and patient-centric issues. **Abstract:** https://goo.gl/EN14ZM

N.B. Additional articles on managing end-of-life medications, particularly in the context of home palliative care, are noted in the 19 June 2017 issue of Media Watch (#517, pp.12-13).

Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care

THE LANCET, 2017;18(9):e543-e551. Advance care planning (ACP) is increasingly implemented in oncology and beyond, but a definition of ACP and recommendations concerning its use are lacking. The authors used a formal Delphi consensus process to help develop a definition of ACP and provide recommendations for its application. Of the 109 experts (82 from Europe, 16 from North America, and 11 from Australia) who rated the ACP definitions and its 41 recommendations, agreement for each definition or recommendation was between 68-100%. ACP was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate. Recommendations included the adaptation of ACP

Cont.

based on the readiness of the individual; targeting. ACP content as the individual's health condition worsens; and, using trained non-physician facilitators to support the ACP process. The authors present a list of outcome measures to enable the pooling and comparison of results of ACP studies. They believe that their recommendations can provide guidance for clinical practice, ACP policy, and research. **Summary:** https://goo.gl/MTjmXv

> **N.B.** Several recently published articles offering a range of perspectives on advance care planning are noted in the 4 September 2017 issue of Media Watch (#526, pp.10-11).
>
> **Related**

- *BRITISH JOURNAL OF NEUROSCIENCE NURSING* | Online – 1 September 2017 – **'The complexities of advance care planning in patients with idiopathic Parkinson's disease.'** The purpose of this article is to review current practice in terms of managing complex issues in the long-term condition of idiopathic Parkinson's disease (IPD). Particular focus is on the optimum time to have end-of-life discussions and the complications that may be involved in cases of IPD. The author looks at the nature of IPD, the different stages of the disease, and the right time for palliative conversations and advance care planning. The range of advanced communication skills needed to have effective conversations will be evaluated, alongside a review of why communication is made more difficult in patients with PD, the impact this has on family members, and the legal and ethical implications, so as to improve practice when making an advance care plan in a patient with IPD. **Abstract:** https://goo.gl/WuRyWq

- *JOURNAL OF NURSING & HEALTH MANAGEMENT* | Online – 1 September 2017 – **'A word of caution about advance directives.'** Advance Directives are often made without the opportunities for full informed consent. On what basis did the patient make the decision that she would not want to be treated? The decision not to receive treatment should be based on a clear understanding of the situation. It is essential that the patient understands the disorder, the available alternatives, and her chances and risks. This can be rather complicated when the physicians themselves do not have a clear picture about the condition and cannot provide a reliable prognosis. Furthermore, there are valid concerns about the patient's opportunity to change her mind, the potential for scientific developments, and the clarity of the advance directive. **Full text:** https://goo.gl/zEVxkB

A test for freedom of conscience under the Canadian Charter of Rights & Freedoms: Regulating and litigating conscientious refusals in health care

MCGILL JOURNAL OF LAW & HEALTH, 2017;11(1):S1-S30. Conscientious refusal to provide insured health care services is a significant point of controversy in Canada, especially in reproductive medicine and end-of-life care. Some provincial and territorial legislatures have developed legislation or regulations, and some professional regulatory bodies have developed policies or guidelines, to better reconcile tensions between health care professionals' conscience and patients' access to health care services. As other groups attempt to draft standards and as challenges to existing standards head to court, the fact the meaning of "freedom of conscience" under the Canadian Charter of Rights and Freedoms is not yet settled will become ever more problematic. In this paper, we review the case law and legislative history relating to freedom of conscience. Having shown that the nature and scope of the freedom of conscience provision cannot be settled by either review, we turn to philosophy for insights with respect to the contemporary purpose of protecting freedom of conscience. On this basis, the authors offer a substantive test for freedom of conscience under the Charter. They do so for two reasons. First, the authors seek to assist those responsible for regulating the conduct of health care professionals in designing and implementing laws and policies that protect and promote the health needs and interests of patients without unjustifiably limiting the Charter conscience rights of health care professionals. Second, they seek to inform the analysis of future freedom of conscience Charter cases in response to the decriminalization of medical assistance in dying and the licensing of the drugs used for medical abortion. **Click on 'Download Article' to access full text:** https://goo.gl/fR4bLr

The current state of palliative medicine in Lebanon

MÉDECINE PALLIATIVE | Online – 4 September 2017 – The development of palliative medicine (PM) is today in a paradox state. Even though official speeches are very encouraging, they are accompanied by scattered means, which are part of a multifaceted, uncertain and anarchic strategy. The main challenge of the transmission of palliative culture, which is an innovative concept in terms of sanitary policies, consists of a "concrete implementation," through a reform of the Lebanese health system. If the "why" of such a policy appears to be appropriate, the "how," however, is to define the orientation that will take PM, the implementation of a strategy for the development of PM, the funding for the treatment of patients with "palliative" status, etc., are essential. However, they need to be discussed with expert PM to manage the obstacles and limitations to the development of this specialty. **Abstract:** https://goo.gl/8DtWk5

N.B. French language article.

Assisted (or facilitated) death

Representative sample of recent journal articles:

- *OMEGA – JOURNAL OF DEATH & DYING* | Online – 5 September 2017 – '**Changing attitudes toward euthanasia and suicide for terminally ill persons, 1977 to 2016: An age-period-cohort analysis.**' Several longitudinal studies show that over time, the American public has become more approving of euthanasia and suicide for terminally ill persons. Yet, these previous findings are limited because they derive from biased estimates of disaggregated hierarchical data. The results of this analysis point toward a continued liberalization of both attitudes over time, although the magnitude of change was greater for suicide compared with euthanasia. More fluctuation in the probability of supporting both measures was exhibited for the age and period effects over the cohort effects. **Abstract:** https://goo.gl/69H4MH

Worth Repeating

The carer persona: Masking individual identities

PERSONA STUDIES, 2015;1(1):65-75. According to Jungian theory, "persona" is a concept reflecting a compromise between the individual and society. In mediating between a person's subjective inner world and the external social world, the persona represents a generalised idea of the self, which builds up from experiences of interacting with society. Such reflections of self-identity can therefore develop across multiple domains of a person's life, culminating in understandings of self in a variety of specific roles. The existence of multiple personas can be clearly demonstrated in the context of people providing unpaid care for a family member or friend who has a disability, mental illness, chronic condition, or who is frail. Carers are likely to possess multiple roles as an individual, existing across various social and personal domains. The author argues that in caring for loved one, a compromise takes place between individual selves and the social caring role. That is, the "carer persona" can mask a carer's individual identities and their associated needs. The potential complexity of caring roles is explored, with an emphasis on acknowledging the personal needs and identities of carers beyond their caring roles. This acknowledge-ment has implications for service delivery and policy development regarding carers and those for whom they care. [Noted in Media Watch 11 May 2015 (#409, p.7)] **Abstract:** https://goo.gl/QKN9aC

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

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: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: https://goo.gl/nZMuK7

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: http://goo.gl/frPgZ5

PALLIATIVE CARE NETWORK COMMUNITY: http://goo.gl/8JyLmE

PALLIMED: http://goo.gl/7mrgMQ
[Scroll down to 'Aggregators' and 'Media Watch by Barry Ashpole']

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: https://goo.gl/lXO4mD

SINGAPORE | Centre for Biomedical Ethics (CENTRES): https://goo.gl/JL3j3C

Canada

CANADIAN SOCIETY OF PALLIATIVE CARE PHYSICIANS: https://goo.gl/BLgxy2
[Scroll down to 'Are you aware of Media Watch?']

ONTARIO | Acclaim Health (Palliative Care Consultation): https://goo.gl/wGi7BD
[Scroll down to 'Additional Resources']

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

ONTARIO | Mississauga Halton Palliative Care Network: https://goo.gl/ds5wYC
[Scroll down to 'International Palliative Care Resource Center hosts Media Watch']

Cont.

Europe

EAPC EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: http://goo.gl/o7kN3W
[Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Magyar Hospice Alapítvány: http://goo.gl/5d1l9K

U.K. | Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

Palliative Care Network Community

Closing the Gap Between Knowledge & Technology

http://goo.gl/OTpc8I

Barry R. Ashpole
Guelph, Ontario CANADA

'phone: 519.837.8936
e-mail: barryashpole@bell.net