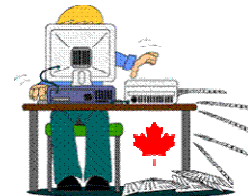


Media Watch...

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.

14 November 2016 Edition | Issue #487



Compilation of Media Watch 2008-2016 ©

Compiled & Annotated by Barry R. Ashpole

Experiencing loss and separation: Scroll down to [Specialist Publications](#) and 'A walk through bereavement theory' (p.7), in *End of Life Journal*.

Canada

Canadians call for palliative care to be enshrined in Canada Health Act

ALBERTA | *The Edmonton Journal* – 9 November 2016 – After hearing from more than 1,500 Canadians in a national survey and meeting with experts for three days in Ottawa, a citizens' lay panel has delivered a Consensus Statement calling for palliative care (PC) to be enshrined in the Canada Health Act, woven into the health care system and guaranteed for all Canadians.^{1,2} The panel called for a stronger, integrated approach to home care, allowing Canadians to be supported at home in their final days. Covenant Health Palliative Institute and 13 of Canada's leading national health organizations led the recent Palliative Care Matters Consensus Development Conference... The lay panel of 12 Canadians heard scientific evidence from an academic expert panel and made several recommendations in their Consensus Statement to improve PC in Canada. The panel ... made 20

specific recommendations. The Palliative Care Matters initiative began with listening to Canadians through focus groups and the Ipsos Research survey and it continued with the Lay Panel members, chosen for their ability to represent the views of broad groups of Canadians. The third and final phase of the initiative will be a report in early 2017 from the Conference Board of Canada which reviews the Consensus Statement and outlines how the recommendations can be implemented. <https://goo.gl/gAfKVP>

Specialist Publications

'The Transplant Palliative Care Clinic: An early palliative care model for patients in a transplant program' (p.6), in *Clinical Transplantation*.

1. 'Canadians' Views of Palliative Care National Online Survey,' Palliative Care Matters, September 2016. [Noted in Media Watch 26 September 2016, #481 (p.1)] <https://goo.gl/Sa6wVV>
2. 'Palliative Care Matters: How Canada's Health System Needs to Change,' Consensus Statement, November 2016. <https://goo.gl/PFvxpM>

Back Issues of Media Watch
<http://goo.gl/frPgZ5>

IPCRC.NET International Palliative
Care Resource Center

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEW BRUNSWICK | CBC News (Fredericton) – 7 November 2016 – ‘**Number of doctor-assisted dying cases revealed by province.**’ CBC News has learned Horizon Health Network, the province’s English health authority, has approved nine doctor-assisted dying cases, a number that was kept secret until now. The data was obtained through the Right to Information Act after the province declined to provide records, citing privacy concerns. Nova Scotia and the Yukon were the only other province and territory that didn’t provide the information to CBC News. The province’s French health authority, Vitalité Health Network, has not yet disclosed the number of people who have been allowed to end their lives with the assistance of a doctor. Even though Horizon Health Network has released the number of approved assisted dying requests, it’s still not clear how many patients followed through with ending their lives. The Department of Health doesn’t have a system to track the number of deaths from both health authorities. A spokesperson for the department said the province is collaborating with the federal government to establish a process for monitoring and reporting on doctor-assisted dying. <https://goo.gl/BMytql>

Noted in Media Watch 19 September 2016, #480 (p.1):

- *THE GLOBE & MAIL* | Online – 13 September 2016 – ‘**We can’t debate the assisted dying law without data.**’ How many legal assisted deaths have there been? No one is really saying – at least not officially. <http://goo.gl/rZcsGd>

U.S.A.

How to spend your final months at home, sweet home

KAISER HEALTH NEWS | Online – 10 November 2016 – There’s no mystery about what older adults want when they become seriously ill near the end of their lives. They want to be cared for at home. For as long as possible. It’s easy to understand why. Home represents familiarity, safety and identity – the place where we belong. Yet health systems aren’t rewarded financially for making “time at home” a priority like they are for reducing the number of patients readmitted to hospitals. Researchers from the Dartmouth Institute for Health Policy and Harvard Medical School argue that should change... Health systems should focus on “outcomes that matter to patients,” they write, citing a new national analysis of terminally ill patients.¹ Where these patients – most of them older adults – spent their last 180 days varied significantly across the country. People had the most time at home in Mason City (145.82 days) and Waterloo, Iowa (144.61 days), and the least time at home in Idaho Falls, Idaho (118.83), and Shreveport, Louisiana. (119.15 days). Multiple factors contributed, including the availability of medical and social services and seniors’ financial and caregiving resources. Do a few more weeks spent at

home matter? Yes, if what patients truly value is taken seriously, the researchers asserted. <https://goo.gl/G0F5U4>

Specialist Publications

‘**Geographic variation in California pediatric hospice care for children and adolescents (2007-2010)**’ (p.4), in *American Journal of Hospice & Palliative Medicine*.

‘**Analysis of U.S. compassionate and geriatric release laws: Applying a human rights framework to global prison health**’ (p.8), in *Journal of Human Rights & Social Work*.

‘**Palliative care for American Indians and Alaska Natives: A review of the literature**’ (p.9), in *Journal of Palliative Medicine*.

‘**Thoughts about ‘Dying in America’: Enhancing the impact of one’s life journey and legacy by also planning for the end of life**’ (p.11), in *Proceedings of the National Academy of Sciences of the United States of America*.

1. ‘Days spent at home – a patient-centered goal and outcome,’ *New England Journal of Medicine*, 27 October 2016. [Noted in Media Watch 31 October 2016, #485 (p.2) <https://goo.gl/d5Mj73>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- COLORADO | *The Denver Post* – 9 November 2016 – ‘**Colorado voters accept right-to-die measure.**’ Colorado passed a medical aid in dying measure ... that will allow adults suffering from terminal illness to take life-ending, doctor-prescribed sleeping medication. <https://goo.gl/GCfr7w>

International

Home care in England

Ombudsman reports “dramatic” increase in home care complaints

U.K. (England) | *LocGov* – 10 November 2016 – The Local Government Ombudsman’s (LGO) review of adult social care complaints 2015-2016 has revealed a dramatic increase in the number of complaints regarding the quality of home care.¹ Those who contacted the LGO complained about a number of issues, including care workers being late for or missing appointments, not staying long enough, and not doing what they should. The Ombudsman upheld 65% of the reports that it investigated in detail... “Our complaints show that for people receiving care in their homes, it’s often the little things that mean so much to them in maintaining their dignity, independence and a good quality of life. Consistency of care is vital to those who rely on these services.” said the Ombudsman Dr. Jane Martin. “We recognise the sector’s work signposting people to us may have had an impact on the number of complaints we received. However, we are still upholding nearly two thirds of home care complaints. This is too many.’ Dr. Martin also warned there may be “further people suffering in silence at home” because those receiving home care have less access to advocacy than those in residential care. Responding to the Ombudsman’s report, Counsellor Izzi Seccombe, chairman of the Local Government Association’s community wellbeing board, warned home care

may only get worse due to funding pressures. <https://goo.gl/QfCGa1>

Local Government Ombudsman’s Review: Case study

End-of-life care left family in distress

Margaret’s family arranged for a care provider to provide end-of-life care for Margaret, including a live-in carer. The care plan encouraged the carer to comply with the family’s wishes about how to care for Margaret, provided they put her at no risk of harm. The aim was for Margaret to live her final days with dignity and support and have a pain free, dignified death. The carer was helping Margaret to eat a dessert. When Margaret refused it, her clothes became soiled. Margaret wanted to be moved to the commode and the carer helped her to do so. The carer suggested that Margaret spend some time outside of the bed and agreed to sit her in a chair she used occasionally to relieve pressure sores. The carer covered Margaret’s lower half with a towel and intended dressing her for bed when she was ready to go back. Margaret wanted some time on her own so the carer told her she would sit in the other room and to call her when she felt ready for bed. The carer failed to leave the call button with Margaret. Margaret died while sitting in the chair, improperly dressed and in soiled clothing

1. ‘Local Government Ombudsman’s Review of Adult Social Care Complaints 2015-2016,’ November 2016. <https://goo.gl/TyEeY2>

Related

- U.K. (England) | *The Daily Telegraph* – 8 November 2016 – ‘**Raft of legal claims against councils feared over cuts to home care.**’ Cash-starved councils are facing a legal challenges from disabled and elderly people deprived of home support, experts have warned. Increasingly patchy service provision due to a forecast £1.9 billion gap in adult social care funding means local authorities are bracing themselves for claims, a new report by three leading think tanks says.¹ <https://goo.gl/dtpHav>

1. ‘The Autumn Statement: Joint Statement on Health & Social Care,’ The Nuffield Trust, The King’s Fund, and the Health Foundation. <https://goo.gl/TmGg7G>

End-of-life care in Australia

Specialist palliative services needed to reduce unnecessary hospitalisation near end of life

AUSTRALIA (Victoria) | *Australian Ageing Agenda* – 9 November 2016 – Almost one in 11 residents who died in their aged care facility were transferred to hospital and returned home in the week prior to their death, according to a Victorian-based study.¹ The researchers found limited involvement in specialist palliative care (PC) services among this group and a potential lack of knowledge and skills in assessing residents and recognising signs of nearing end of life. The study ... looked at the resident deaths of a large not-for-profit provider with 13 facilities and more than 800 beds, all of which had access to local specialist PC services, across metropolitan and regional Victoria from July 2014 to June 2015. Of the 252 deaths in that year, the vast majority occurred in the facility (86%). But 9% of these residents were transferred to hospital and returned home in the last week of their life. Nearly one-third of this group died within 24 hours of returning home and more than half died within two days. A quarter of these residents received PC services prior to going to hospital, a further 37% were referred to services by the hospital before going home and two residents transferred direct to hospice care, suggesting a need for improved access to services, the research found. The study identified opportunities to improve access to services through early referral or universal PC service access. <https://goo.gl/xIC6Gs>

1. 'Supporting a good life and death in residential aged care: an exploration of service use towards end of life,' *International Journal of Palliative Nursing*, 26 September 2016. <https://goo.gl/exOQYa>

Specialist Publications

Geographic variation in California pediatric hospice care for children and adolescents (2007-2010)

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 11 November 2016 – Almost 90% of the children and adolescents [included in this study] had a potential need for hospice care, whereas more than 10% had a realized need. There were distinctive geographic patterns of potential and realized need with high density of potential and realized need in Los Angeles and high density of realized need in the San Diego area. The supply of pediatric hospice care generally matched the needs of children and adolescents. <https://goo.gl/cNz7bu>

Double Parallel Curriculum in Palliative Care

Teaching learners to teach end-of-life care at the bedside

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 7 November 2016 – Physicians are often uncomfortable caring for dying patients. Learners have limited exposure to curriculum on caring for dying patients and often navigate these encounters without appropriate skills and confidence. The authors developed and implemented the Double Parallel Curriculum in Palliative Care (DP-PC): End-of-Life module, which focuses on teaching third-year medical students to not only take care of patients in their last hours of life, but give learners the confidence to teach patient's families what to expect as they hold vigil at their loved one's bedside. The DP-PC is a technology-savvy educational intervention that improves learner confidence and knowledge toward caring for dying patients and their families. Easy access, technology-based teaching tools may enhance bedside teaching of health-care learners and improve the care of patients and their families at the end of life. <https://goo.gl/1eQUHv>

Cont. next page



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 p.13.

Selected articles on “bedside learning” in the context of end-of-life care

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 18 October 2016 – ‘**Palliative care bedside teaching: A qualitative analysis of medical students’ reflective writings after clinical practices.**’ A short bedside clinical experience in palliative care, encouraging student reflection, provides a deeper understanding of PC and even of core medicine values. The data the authors gathered cannot explain only new skill acquisition, but seems to suggest a life-changing personal experience for the student. [Noted in Media Watch 24 October 2016, #484 (p.13)] <https://goo.gl/sYD5Zl>
- *ANNALS OF BEHAVIORAL SCIENCE & MEDICAL EDUCATION*, 2015;21(1):3-5. ‘**Lessons about dying and death from the classroom of the bedside.**’ Neither life experience nor lecture style pedagogy is an adequate substitute for teaching medical students and residents about caring for the terminally ill. Obstacles to involving trainees in the bedside care of the dying include a general cultural avoidance of death, discomfort among faculty mentors when dealing with death, and uneven application of established rubrics for conveying the art of bedside care of the dying. [Noted in Media Watch 6 July 2015, #417 (p.8)] <https://goo.gl/zyASrL>
- *JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, 2014;311(19):1971-1972. ‘**Bedside teaching rounds reconsidered.**’ Barriers to bedside teaching are insufficient time to teach, dependence of diagnosis on technology, obstacles created by infection control, and distractions from clinical responsibilities at distant computer stations. Many teachers find bedside teaching inherently difficult: [Noted in Media Watch 2 June 2014, #360 (pp.8-9)] <https://goo.gl/uz49YS>

“I just think that we should be informed”

A qualitative study of family involvement in advance care planning in nursing homes

BMC MEDICAL ETHICS | Online – 10 November 2016 – In this study, the authors found that patients and relatives can be perceived as intertwined units. The ways they were connected and how the relations were talked about, especially by the family members, confirm that family matters morally in an instrumental as well as an intrinsic way. The authors also found that if the aim of ACP is to get to know important issues and values to frail elderly patients, family members may play a very important role. This is because they know the patient in a different way than the staff; they know about the patient’s life story, and they were also able to make meaningful connections between the patients’ former life and the present situation. If ACP-conversations are carried out soon after admission to the nursing home, the involvement of family members may be even more essential. The third result indicates that to help health care professionals facilitate a conversation on future end-of-life care, a possible way to start is to ask the patient about earlier experiences and memories of loss and sorrow. These experiences are often part of a larger family story, and could be shared by the patient and relatives together. To be open to family ethics when planning for the patient’s future in the nursing home is to be open to diversity and nuances, and to the significance of the patient’s former life and experiences. <https://goo.gl/B6y6G9>

Noted in Media Watch 26 September 2016, #481 (p.9):

- *HEALTH SOCIAL WORK* | Online – 13 September 2016 – ‘**Analysis of advance directive documentation to support palliative care activities in nursing homes.**’ At the initial phases of the intervention, 50% of the [1,877] records [analysed] contained an advance directive (AD). Of the ADs in the resident records, 55% designated a durable power of attorney for health care, most often a child (62%), other relative (14%), or spouse (13%). <https://goo.gl/w6GYOz>

Noted In Media Watch 28 March 2016, #455 (p.7):

- *AGE & AGING* | Online – 24 March 2016 – ‘**Discussing end-of-life issues in nursing homes: A nationwide study in France.**’ In this post-mortem cohort study in a nationwide, representative sample of 78 nursing home facilities in France end-of-life issues were discussed with at most 21.7% of the residents who died during the study period. In one-third of the situations, no discussion about end-of-life-related topics ever occurred, either with the resident or with the relatives. <http://goo.gl/IP8DWX>

Interventions and decision-making at the end of life: The effect of establishing the terminal illness situation

BMC PALLIATIVE CARE | Online – 7 November 2016 – The results of this research highlight that the care received in hospital environments by patients who are in the terminal phase of their disease is characterized by the continuation of numerous interventions and therapeutic decisions that are typical for acute disease and far from the objectives of palliative care. When there is an explicit reference to the terminal phase of a disease in clinical histories, the number of interventions is reduced, and the number of end-of-life-related decisions is increased. However, for many routine interventions, patients continue to be treated like any other patient despite the registration of their terminal situation in the clinical history. According to these conclusions, it is necessary to undertake without delay educational interventions to improve the training of all professionals of acute care hospitals involved in the care of patients in a terminal illness situation. Secondly, it is also necessary to involve health managers, in the implementation of interventions and procedures to improve management of terminal illness situation in hospital settings, including improving data collected in clinical histories. <https://goo.gl/PGXAso>

The Transplant Palliative Care Clinic: An early palliative care model for patients in a transplant program

CLINICAL TRANSPLANTATION | Online – 4 November 2016 – Although patients within a transplant program are awaiting or have received disease modifying or curative treatment, they are also facing advanced illness and the possibility of death. The involvement of specialized palliative care (PC) services for these patients may improve symptom management and facilitate advance care planning. However, patients in organ transplantation programs have difficulty accessing PC resources and often do so only sporadically in the inpatient setting. Currently, there is little access to ambulatory PC for these patients and there have been no descriptions of programs delivering such care in the medical literature. The authors outline the development and structure of a Transplant Palliative Care Clinic within the University Health Network's Multi-Organ Transplant Program, in Toronto, Canada. <https://goo.gl/m3q3Nx>

Noted in Media Watch 27 January 2014, #342 (p.10):

- *EUROPEAN JOURNAL OF PALLIATIVE CARE*, 2014;21(1):30-33. **'More palliative care involvement is needed for transplant patients.'** Patients who have already received a transplant, as well as those who are on a waiting list for an organ transplant, have large unmet needs for high-quality palliative and end-of-life care. At Harefield Hospital, a major U.K. cardiothoracic surgery centre, all patients assessed for suitability for lung transplant are offered a holistic assessment by the supportive and palliative care team.

N.B. Access to the *European Journal of Palliative Care* requires a subscription: <https://goo.gl/vpZhCy>

Noted in Media Watch 8 July 2013, #313 (p.10):

- *PULMONARY & RESPIRATORY MEDICINE* | Online – 24 June 2013 – **'Barriers to the provision of optimal palliative care in a patient awaiting lung transplantation.'** This case report describes palliative and end-of-life care in a patient with end stage pulmonary fibrosis listed for lung transplantation and discusses the transition from curative restorative care and care to end-of-life. The goals of care of patients waiting for lung transplantation should be reviewed regularly and clarified as the clinical condition of the patient changes. <https://goo.gl/nEHb6j>



Closing the Gap Between Knowledge & Technology

Fostering education and interaction, and the exchange of ideas, information and materials.

<http://goo.gl/OTpc8l>

Quality end-of-life cancer care: An overdue imperative

CRITICAL REVIEWS IN ONCOLOGY/HEMATOLOGY | Online – 3 November 2016 – This review assesses the current status of end-of-life care (EOLC) based on large-scale, multi-year nationwide surveys of treatment modality, setting, and cost of care during terminal patients' last months of life. It shows that EOLC goals often remain sub-optimal. Contributing factors include prioritized life preservation, uneven commitment to palliative care (PC), few PC specialists, and perverse financial incentives that encourage costly interventions. Although not determinant *per se*, these factors coupled to doubts about what constitutes end-of-life can lead to overextended disease treatment and a late implementation of PC. In order to bridge the existing gap between care received and care expected and achieve quality end-of-life and promote death with dignity, the authors propose both to view the person rather than the disease as the unit of care and a pragmatic definition of end-of-life. Such a strategy should facilitate selecting an optimal time to transition from disease-targeted treatment to PC. <https://goo.gl/1NI69m>

Noted in Media Watch 7 November 2016, #486 (p.8):

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 31 October 2016 – ‘**Integration of palliative care into standard oncology care: American Society of Clinical Oncology Clinical Practice Guideline updated.**’ The updated guideline reflects changes in evidence since the previous guideline. It is recommended that inpatients and outpatients with advanced cancer should receive dedicated palliative care services early in the disease course, concurrent with active treatment. <https://goo.gl/zaRNuP>

A walk through bereavement theory

END OF LIFE JOURNAL | Online – 10 November 2016 – This paper examines and discusses specific grief theories that have emerged over a number of years, resulting in an overview of some of the main theories for the reader. The roots of bereavement theory, found in the health-related literature, lie mainly within psychiatry and psychology, which may explain some of the reluctance of general nurses to engage with this literature and area of health care. The application of bereavement support in practice is important and detailed discussion of a practical application will be discussed in another paper; however, initial understanding of bereavement theory enables staff to begin to support patients and carers in an informed manner. No theory is absolute, and it is unlikely that any bereaved person follows the pattern of an individual theory as written, instead presenting a unique individual adaptation of parts of theories to reflect their personality and history. <https://goo.gl/h2FTaA>

Related

- *BMC PALLIATIVE CARE* | Online – 8 November 2016 – “**It still haunts me whether we did the right thing.**” **A qualitative analysis of free text survey data on the bereavement experiences and support needs of family caregivers.**’ This paper adds new insights to the limited evidence available on the specific effects that caring for a loved one at the end of life can have on bereavement experiences. These are based on the first hand experiences of family members, the second hand observations of health and social care professionals, or in many cases a combined perspective brought by bereaved professionals, which were articulated in “free text” written responses to a self-completed survey. <https://goo.gl/0QRrP>

Patterns of care in hospitalized vascular surgery patients at end of life

JAMA SURGERY | Online – 2 November 2016 – Why do vascular surgery patients and their families choose comfort care, and how well are we using palliative care (PC) teams and advance directives (ADS)? This cohort study of medical records of patients at the end of life found that most vascular surgery patients who die while hospitalized are placed on comfort measures, but few had ADs or a PC consultation. Number of days in the intensive care unit or receiving mechanical ventilation, needing a tracheostomy, or requiring dialysis correlated with transition to comfort care. Preoperative advance care planning may improve care in older, sicker patients at the end of life. <https://goo.gl/8ip9Wb>

Cont.

Commentary

- *JAMA SURGERY* | Online – 2 November 2016 – ‘**Limiting care for surgical patients at the end of life.**’ This thought-provoking study ... discovered that 73% of the patients died after the initiation of comfort care measures. In other words, most patients on a surgical service no longer die unexpectedly. A decision is made to allow them to die. The therapeutic goals change from rescue to palliation. <https://goo.gl/505rIP>

What is the potential of community paramedicine to fill rural health care gaps?

JOURNAL OF HEALTH CARE FOR THE POOR & UNDERSERVED, 2016;27(4):144-158. Community paramedicine (CP) uses emergency medical services (EMS) providers to help rural communities increase access to primary care and public health services. This study examined goals, activities, and outcomes of 31 rural-serving CP programs through structured interviews of program leaders and document review. Common goals included managing chronic disease (90.3%); and reducing emergency department visits (83.9%), hospital admissions/readmissions (83.9%), and costs (83.9%). Target populations included the chronically ill (90.3%), post-hospital discharge patients (80.6%), and frequent EMS users (64.5%). Community paramedicine programs engaged in bi-directional referrals most often with primary care facilities (67.7%), hospitals (54.8%), and home health (38.7%). Programs provided assessment, testing, preventive care, and post-discharge services. Reported outcomes were promising, but few programs used rigorous evaluation methods. Rural-serving CP programs provided services to shift costs to less expensive settings and provide appropriate care where vulnerable patients live, but more evidence is needed that care is safe, effective, and economical. <https://goo.gl/UfYKRm>

Noted in Media Watch 9 November 2015, #435 (p.9):

- *AUSTRALASIAN JOURNAL OF PARAMEDICINE*, 2015;12(5):Article #3. ‘**Paramedics’ perceptions and educational needs with respect to palliative care.**’ Paramedics [i.e., survey respondents] have a sound grasp of some important aspects of palliative care (PC), including symptom control and the holistic nature of the palliative approach. They did, however, tend to equate PC with care occurring in the terminal phase and saw it as being particularly applied to cancer diagnoses. Paramedic PC educational efforts should be focused on: 1) Ethical issues; 2) End-of-life communication; 3) Increasing understanding of the common causes of death; and, 4) Education regarding those illnesses where a palliative approach might be beneficial. <https://goo.gl/MqXvRk>

Analysis of U.S. compassionate and geriatric release laws: Applying a human rights framework to global prison health

JOURNAL OF HUMAN RIGHTS & SOCIAL WORK | Online – Accessed 8 November 2016 – A content analysis of 47 identified federal and state laws was conducted using inductive and deductive analysis strategies. Of the possible 52 federal and state corrections systems (50 states, Washington DC, and Federal Corrections), 47 laws for incarcerated people, or their families, to petition for early release based on advanced age or health were found. Six major categories of these laws were identified: 1) Physical/mental health; 2) Age; 3) Pathway to release decision; 4) Post-release support; 5) Nature of the crime (personal and criminal justice history); and, 6) Stage of review. Recommendations are offered, for increasing social work policy and practice expertise, and advancing the rights and needs of this population in the context of promoting hu-

man rights, aging, health, and criminal justice reform. <https://goo.gl/4wqwc3>

Extract from the *Journal of Human Rights & Social Work* article

Eighteen of the laws noted that the medical hospital or hospice, or family home with healthcare professionals, must be vetted prior to release to ensure both safety and proper healthcare. In addition, 11 of the laws mentioned that the incarcerated person must have financial resources to cover healthcare, such as Medicaid, in place prior to early release. Five of the laws mentioned a holistic style of care, including emotional support for the incarcerated person and family, as well as reintegration support.

Cont.

N.B. End-of-life care in the prison system has been highlighted on a regular basis in Media Watch. A compilation of the articles, reports noted in past issues of the weekly report is available at: <http://goo.gl/ZpEJyQ>
See also 'Do we care about old people behind bars, and should we?' The Conversation (Australia), 7 November 2016. <https://goo.gl/e9muOB>

Palliative care for American Indians and Alaska Natives: A review of the literature

JOURNAL OF PALLIATIVE MEDICINE | Online – 9 November 2016 – Little is known about optimal palliative and end-of-life care for American Indians and Alaska Natives (AIs/ANs). The authors' search strategy yielded 294 references, of which they included 10 publications. Study methods and outcome measures were heterogeneous, and many studies were small and/or subject to multiple biases. Common themes included the importance of culturally appropriate communication, multiple barriers to treatment, and less frequent use of advance directives than other populations. Heterogeneity of study types, population, and small sample sizes makes it hard to draw broad conclusions regarding the best way to care for AIs/ANs. More studies are needed to assess this important topic. <https://goo.gl/DTw0oW>

Noted in Media Watch 15 September 2014, #375 (p.13):

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2014;16(7):404-413. '**American Indians' experiences of life-threatening illness and end of life.**' The study focus was identification of tribal values, contributing factors, and decision making regarding end of life. Participants' end-of-life experiences focused on the concept of struggle, coping by seeking knowledge, and applying connectedness to family, community, spirituality, and health care providers. Their culturally ideal end of life was identified as being a proud Indian and living the Indian way of life to the end. <https://goo.gl/W0VORL>

Economics of palliative care: Measuring the full value of an intervention

JOURNAL OF PALLIATIVE MEDICINE | Online – 8 November 2016 – The importance of developing and strengthening the evidence base on palliative care (PC) is well established. Fiscal pressures and rising healthcare costs among seriously ill populations who often receive inappropriate care make health economics a key part of this research agenda. Randomized trials reporting high-level evidence or survival effects provided new insight into the value of PC interventions. These studies also have important implications for the economics of PC as currently practiced and understood. The purpose of this article is to highlight the most important of these implications, and to give food for thought to investigators planning studies to strengthened the economic evidence based on PC. There are fundamentally two challenges in economic evaluation of healthcare: the measurement of treatment effect on costs and measurement of effects on outcomes, and the authors discuss issues in both domains in turn. <https://goo.gl/Z8apMe>

Noted in Media Watch 31 October 2016, #485 (p.8):

- *PALLIATIVE MEDICINE* | Online – 25 October 2016 – '**Finding evidence about the costs of palliative care: CareSearch's suite of search tools.**' This paper describes the development of a resource that facilitates the retrieval of current high quality literature about economic aspects of palliative care and highlights the importance of searching in multiple and appropriate databases for economics literature. The paper outlines the identification, testing and evaluation of existing search filters and other sources of information to determine the best resources to use and the best terms to use for each one. <https://goo.gl/QdzZqb>

Noted in Media Watch 12 March 2014, #357 (p.10):

- *EXPERT REVIEW OF PHARMACOECONOMICS & OUTCOMES RESEARCH* | Online – 2 May 2014 – '**Strategies for the economic evaluation of end-of-life care.**' This paper examines different theoretical perspectives from which economic evaluation of end-of-life care could be conducted, and argues for the application of a capability approach focusing on the opportunity for a good death. <https://goo.gl/noiZRW>

Palliative care for ICU families: More harm than good?

MEDSCAPE CRITICAL CARE | Online – 9 November 2016 – The medical community has widely believed that providing information and support to families of acutely and critically ill patients during periods of the illness is both appropriate and beneficial to the family. This study¹ is the first multicenter randomized trial of a palliative care (PC) support intervention for family surrogate decision makers, particularly in patients with chronic critical illness, and these findings do not support routine use of PC-led discussions of goals of care for all families of patients with chronic critical illness. Moreover, these findings suggest that providing PC could even be harmful to the family caregivers by creating additional distress that endures and leads to PTSD. It is possible that these results occurred by chance or that they only occurred with this specific group of patients and were the result of the very specific intervention that was delivered in this trial. However, it's more important to consider these findings in the broader context of how we ensure the best care for both patient and family: the goals of patient- and family-centered care. We continue to struggle with knowing what patients and families understand and want during the course of critical illness. This study forces us to step back and ask some very basic questions: What information should we convey to patients and families, what is the best way to do it, and what is the purpose of doing it? With this new study in mind, we need to reconsider how we use ancillary information-sharing and decision-making services (like PC experts) in the ICU and reconsider our approach based on our shared goals. In this way, we can provide the best care without further increasing distress among patients and family members. <https://goo.gl/XpW7yJ>

1. Effect of palliative care-led meetings for families of patients with chronic critical illness: A randomized clinical trial, *Journal of the American Medical Association*, 2016;316(1):51-62. [Noted in Media Watch 11 July 2016, #470 (p.15)] <http://goo.gl/YnECmQ>

N.B. Additional articles on family conferences in the context of end-of-life care noted in Media Watch 8 August 2016, #474 (p.11).

Enhancing psychosocial and spiritual palliative care: Four-year results of the program of comprehensive care for people with advanced illnesses and their families in Spain

PALLIATIVE & SUPPORTIVE CARE | Online – 7 November 2016 – The authors describe the results of a La Caixa Foundation and World Health Organization Collaborating Center Program, 'Comprehensive Care for Patients with Advanced Illnesses and their Families,' after four years of experience. The effectiveness of psychosocial interventions was assessed at baseline (visit 1) and after four follow-up visits. The following dimensions were assessed: 1) Mood state; 2) Discomfort; 3) Anxiety; 4) Degree of adjustment or adaptation to disease; and, 5) Suffering. They also assessed the four dimensions of the spiritual pain scale: 1) Faith or spiritual beliefs; 2) Valuable faith or spiritual beliefs; 3) Meaning in life; and, Peace of mind/forgiveness. The authors built 29 psychosocial support teams involving 133 professionals – mainly psychologists and social workers. During the study period, 8,964 patients and 11,810 family members attended. Significant improvements were observed in the psychosocial and spiritual dimensions assessed. Patients, family members, and stakeholders all showed high levels of satisfaction. This model of psychosocial care could serve as an example for other countries that wish to improve psychosocial and spiritual support. The results confirm that specific psychosocial interventions delivered by well-trained experts can help to ease suffering and discomfort in end-of-life and palliative care patients, particularly those with high levels of pain or emotional distress. <https://goo.gl/BCRmgv>

Related

- *PALLIATIVE MEDICINE* | Online – 9 November 2016 – '**Training hospital staff on spiritual care in palliative care influences patient-reported outcomes: Results of a quasi-experimental study.**' The effects of spiritual care training can be measured using patient-reported outcomes and seemed to indicate a positive effect on the quality of care. Future research should focus on optimizing the spiritual care training to identify the most effective elements and developing strategies to ensure long-term positive effects. <https://goo.gl/vNJhEV>

How should realism and hope be combined in physician-patient communication at the end of life? An online focus-group study among participants with and without a Muslim background

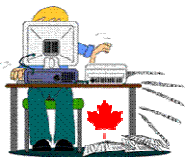
PALLIATIVE & SUPPORTIVE CARE | Online – 7 November 2016 – Maintaining false hope may result in prolonged curative aggressive treatments until the very last stage of life. In this study, the authors explored how people think that realistic and hopeful information should best be combined in physician-patient communications at the end of life. A variety of people participated [in focus groups]: patients, older people, relatives, and healthcare professionals with and without a Muslim background. Participants with a Muslim background constituted a separate group, because previous research indicated that they might have distinct views on good end-of-life care and communication. Participants from all focus groups preferred that physicians provide realistic information in an empathic way, stating that the patient would never be left on his own and that withholding curative treatment was not equal to withholding care, explicitly asking how the patient could be helped during the time remaining, and involving other professionals in the care process and communications. As such, physicians could support patients' transition from "hope for a cure" to "hope for a good death." Muslims specified the way they wished to receive realistic information: first from a relative, and not by using the term "incurable illness," but rather by informing the patient that they had no remaining curative treatments available. Realism and hope are not necessarily mutually exclusive and can be combined when providing realistic information in a delicate and culturally sensitive way. This study provides suggestions on how physicians can do so. <https://goo.gl/kM68eB>

N.B. Additional articles on the Islamic perspective on end-of-life and end-of-life care noted in Media Watch 7 November 2016, #486 (p.10).

Thoughts about 'Dying in America': Enhancing the impact of one's life journey and legacy by also planning for the end of life

PROCEEDINGS OF THE NATIONAL ACADEMY OF SCIENCES OF THE UNITED STATES OF AMERICA | Online – 8 November 2016 – 'Dying in America' made five recommendations to improve quality and honor individual preferences near the end of life (EOL)¹ beginning with making conversations with providers and families something that occurs during various phases of the life cycle and not just when one is facing serious illness or possible EOL. It was recommended that: 1) Public and private payers and care delivery organizations cover the provision of comprehensive care that is accessible and available to individuals on a 24/7 schedule; 2) Professional societies and other entities establish standards for clinician patient communication and advance care planning and that payers and care delivery organizations adopt them; 3) Educational institutions, credentialing bodies, accrediting boards, state regulatory agencies, and care delivery organizations establish palliative care training, certification, and/or licensure requirements; 4) Public and private payers and care delivery organizations integrate the financing of health and social services; and, 5) Public and private organizations should engage their constituents and provide fact-based information to encourage advance care planning and informed choice. <https://goo.gl/4VfAW6>

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 Media Watch, 22 September 2014, #376 (p.4)] <http://goo.gl/6Q5VNY>



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>

Worth Repeating

Requests for non-disclosure of poor prognoses to patients

END OF LIFE JOURNAL, 2013;3(4). For patients who are given information about a life-limiting diagnosis and poor prognosis, it can be very distressing to hear words such as “terminal” and “end of life.” These words are also upsetting for patients’ family members/loved ones. In some instances, the family or surrogate decision-makers may ask that health professionals withhold the prognosis and distressing terminology by requesting non-disclosure of this health information to their loved one. These types of situations can be stressful to the healthcare professional and ethically problematic. Healthcare professionals may feel torn between doing what they perceive as being in the best interests of the patient and complying with the family’s request for non-disclosure. This article explores the distress that being told about terminal prognoses causes patients and family members/loved ones and highlights some of the reasons for families requesting non-disclosure of terminal diagnosis. Cultural considerations for such requests, effects of non-disclosure on patients and ways in which to resolve the conflict are also discussed. [Noted in Media Watch 9 December 2013, #335 (p.9)] <https://goo.gl/FjxlmF>

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: Behind the Scenes
<http://goo.gl/XDjHxz>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <https://goo.gl/WAbX4S>

Link updated 11.09.2016

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 Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <HTTP://GOO.GL/JNHVMB>

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

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): <https://goo.gl/IOSNCZ>

Link updated 11.09.2016

Europe

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

HUNGARY | Hungarian Hospice Foundation: <http://goo.gl/5d1l9K>

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

Barry R. Ashpole
Guelph, Ontario CANADA

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