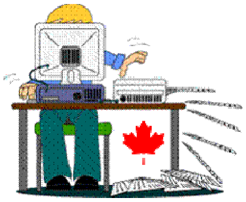
Media Watch... *is intended as an advocacy, research and teaching tool. The weekly report is international in scope and distribution – to colleagues who are active or have a special interest in **hospice** and **palliative care**, and in the quality of **end-of-life care** in general – to help keep them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

21 November 2016 Edition | Issue #488



Compiled & Annotated by Barry R. Ashpole

End-of-life communications: Scroll down to Specialist Publications and 'Wished for and avoided conversations with terminally ill individuals during final conversations' (p.8), in *Death Studies*.

Canada

Queen's Park votes favourably on end-of-life Dan's Law

ONTARIO | *The Windsor Star* – 17 November 2016 – Dan's Law [i.e., Bill 54 to amend the Home Care & Community Services Amendment Act (1994)], named for a former General Motors' (GM) transmission plant worker who died of cancer while fighting for the right to receive home care, has passed second reading at Queen's Park [i.e., the provincial parliament]... Dan Duma moved to Alberta with his wife to find work after the Windsor GM plant closed. Diagnosed with liver cancer and given just a short time to survive, he chose to move back to Windsor to live at the home of one of his daughters for his final days. But home care is currently not subject to Canada's inter-provincial billing agreement. One month into the three-month waiting period for Ontario Health Insurance Program coverage while living with his daughter, and having not been eligible for public home-care assistance, Duma died. Dan's Law seeks to eliminate the waiting period for home and community care when someone takes up residence in Ontario after residing in another Canadian province. https://goo.gl/NVLUTR

N.B. Bill 54, a private member's bill, has now been referred to the Standing Committee on Justice Policy.

Noted in Media Watch 31 October 2016, #485 (p.1):

- ONTARIO | *The Globe & Mail* – 24 October 2016 – **'Home-care coverage gap remains for patients who move provinces.'** When Dan Duma found out he had incurable liver cancer, he wanted to die at home. For the Alberta oil-sands worker, that meant moving back to Windsor, Ontario, where he and his wife lived for more than 15 years before the closing of the local General Motors plant pushed them west, and where their two grown daughters live now. Unfortunately for Mr. Duma, crossing provincial lines left him with no access to publicly funded home care for three months, making it impossible for the 48-year-old to be at home when he died on 18 July. https://goo.gl/R8V79Z

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- MANITOBA | CBC News (Winnipeg) – 18 November 2016 – **'Faith-based hospitals in Winnipeg ban medically assisted deaths.'** Both Concordia Hospital (Anabaptist-Mennonite) and St. Boniface Hospital (Catholic) say they will not offer the legal service to patients. In June, the federal government amended the criminal code with Bill C-14 to allow doctors and nurse practitioners to help patients with "grievous and irremediable" illnesses to die. Manitoba introduced its own policy to implement medical assistance in dying ... that same month. https://goo.gl/val6fU

Specialist Publications

'The annals of medical assistance in dying' (p.14), in *Annals of Internal Medicine*.

U.S.A.

Is grief a disease?

A new theory is challenging the way psychologists understand mourning

THE ATLANTIC | Online – 16 November 2016 – Grief, by definition, is the deep, wrenching sorrow of loss. The initial intense anguish, what [Columbia University psychiatrist Katherine] Shear calls acute grief, usually abates with time. Shear says that complicated grief is more chronic and more emotionally intense than more typical courses through grief, and it stays at acute levels for longer. Women are more vulnerable to complicated grief than men. It often follows particularly difficult losses that test a person's emotional and social resources, and where the mourner was deeply attached to the person they are grieving. Researchers estimate complicated grief affects approximately 2-3% of the population worldwide. It affects 10-20% of people after the death of a spouse or romantic partner, or when the death of a loved one is sudden or violent, and it is even more common among parents who have lost a child. Clinicians are beginning to acknowledge how debilitating this form of grief can be. https://goo.gl/6YuQai

Quotable Quotes

Grief is not a disorder, a disease or a sign of weakness. It is an emotional, physical and spiritual necessity, the price you pay for love. The only cure for grief is to grieve. Earl A. Grollman, American death educator and counselor.

Specialist Publications

'Bereavement: An anthropological approach' (p.8), in *Death Studies*.

American Association for Retired Persons

Study: Many caregivers spend $7,000 annually out-of-pocket

KAISER HEALTH NEWS | Online – 14 November 2016 – More than 3 out of 4 caregivers absorb out-of-pocket costs currently averaging nearly $7,000 a year, American Association for Retired Persons (AARP) has found.[1] Those costs consumed the equivalent of a fifth of caregivers' incomes on average – and the burdens were even greater for those with lower incomes... The most financially strapped caregivers tap savings or take out loans to meet expenses. AARP conducted its survey of 1,864 family caregivers in July and August. Participants also kept diaries tracking their personal spending. "As technology increases and people live longer and live with more complex care needs, the family has been picking it up, not the formal health care system," said Susan Reinhard, senior vice president and director of AARP's Public Policy Institute. https://goo.gl/sKD74n

Cont.

1. 'Family Caregivers & Managed Long-Term Services & Supports,' American Association for Retired Persons, Public Policy Institute, November 2016. https://goo.gl/dZOTf3

Noted in Media Watch 22 September 2014, #376 (p.5):

- *USA TODAY* | Online – 15 September 2014 – **'A third of family caregivers spend over $10,000 a year.'** About a third of family caregivers spend more than 30 hours a week on caregiving tasks, a survey shows.[1] And about a third spend more than $10,000 a year on caregiving expenses, such as medications, medical bills, in-home care, and in some cases senior housing. The survey found that 46% of family caregivers spend more than $5,000 a year on out-of-pocket caregiving expenses; 32% spend less than $5,000; and, 21% don't know how much they spend. https://goo.gl/u8ptH5

    1. 'Senior Care Cost Index,' September 2014, Caring.com. https://goo.gl/VazY0I

Researchers dissect end-of-life care practices, issue best practices

MCKNIGHT'S | Online – 14 November 2016 – Making sure care preferences are consistently recorded and updated in medical records is crucial to providing quality end-of-life care, researchers stress in a recently published report.[1] Advanced care planning (ACP) is an important step for patients and families to take, especially at a time when nearly a quarter of hospitalized older adults are not able to make their own end-of-life decisions. But inconsistencies in the way care preferences are documented and carried out by nursing homes and hospitals may mean a patient's' preferences are not honored. The team's report ... set out to measure care consistency with documented care practices, and how healthcare providers can improve that consistency [see sidebar, 'Best practices...']. "This paper delves into an issue important to both patients and providers – consistency with documented care preferences," said lead researcher Kathleen Unroe... "We investigated the practicality of implementation of quality metrics to measure consistency of care with ACP and what barriers exist to putting these metrics into practice." Report co-author Alexia Torke added: "ACP is a process, not just a form. It is important that when a person faces serious illness and can no longer make decisions, the care they receive is consistent with the wishes they have previously expressed." https://goo.gl/x6sCMA

Best practices for providers to ensure consistency with their residents care preferences

Documenting each resident's specific treatment preferences – such as "do not place feeding tube" instead of "comfort care" – in the medical record.

Making sure treatment preferences are recorded in a consistent format and location in each medical record.

Reviewing and updating preferences regularly as residents' clinical conditions change.

Creating data collection strategies to document decisions to withhold medical interventions.

Implementing a consistent measurement approach, such as a required percentage for agreement with care preferences, that can be used to compare with other providers.

Specialist Publications

'Quality of Physician Orders for Life-Sustaining Treatment (POLST) forms completed in nursing homes' (p.10), in *Journal of Palliative Medicine.*

1. 'Care consistency with documented care preferences: Methodologic considerations for implementing the Measuring What Matters quality indicator,' *Journal of Pain & Symptom Management*, 24 September 2016. [Noted in Media Watch 26 September 2016, #481 (p.9)] https://goo.gl/SyVpL1

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.15.

International

Giving sick children dignity in death

CHINA | *The China Daily* (Beijing) – 16 November 2016 – Zhou Xuan, an oncologist at the Beijing Children's Hospital, clearly remembers seeing a dying boy pressing his face against the window beside his bed. "He was about 2, and had acute myeloid leukemia. For most of the four months he stayed on the ward, he longed to go outside and play, a request repeatedly turned down by his mother who was worried about his physical condition," she said. "Weeks later, I came across the boy's mother at the hospital. She was traumatized by his death, and by the fact that she had refused his 'one last wish.'" Zhou said. "Sadly, regrets are common among parents, who are focused too single-mindedly on seeking a cure for their dying child." She said the success of children's palliative care (PC) in China will depend on whether parents can accept that the process is not about "giving up," but about "making peace with oneself while having a dignified, less-painful exit from life's stage. In the West, this is done by specially trained teams of doctors, nurses and social workers who work together with a patient's doctors to weave an extra layer of support for the patients and their families. In China now, my team of doctors and nurses have to undertake dual roles." Strangely, this arrangement may better suit the current situation... https://goo.gl/6GJw9p

Specialist Publications

'Partnership working between hospice and children's community nursing teams' (p.7), in *Nursing Children & Young People.*

Parkinson's UK

National Health Service continuing healthcare system "failing most vulnerable"

U.K. (England) | BT.com – 14 November 2016 – National Health Service continuing healthcare enables people with the most complex and serious health needs to have all their care – including nursing home and social care – paid for by the health service. But the system is mired in controversy over the criteria used to check whether people are eligible, with charities warning those who should receive help are being shut out. A new report[1] ... describes the system as complicated, confusing and intimidating. A poll of 274 people who have applied for continuing care for themselves, friends and family showed that 54% felt they were not provided with enough information about the process or given support with the application. Two-thirds (66%) also felt that those involved in assessing their needs had very little or no in-depth knowledge about their illness. Of those who had been advised by assessors that their application would be successful, 35% then had that decision rejected by a review panel. A further survey of 409 health and social care professionals working in continuing care found 78% thought the system was difficult or very difficult for patients and their families to navigate. https://goo.gl/Q3Tyl3

Extract from Parkinson's UK report

At this time our palliative care consultant said she didn't think dad had long to live. Despite this, the assessment didn't happen quickly, and took place in mid-February. I experienced so much worry and anxiety during this time, as I waited to find out whether he would be eligible. Though logically, I didn't know how much more could have been wrong with him in order to make him qualify. When the assessor finally came, it was clear to me she didn't know anything specific about motor neuron disease. She said they should only be doing fast track assessments for someone who is end of stage and then followed that by saying, "which he clearly is not." Dad died two days later.

Specialist Publications

'What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large U.K. city' (p.7), in *BMJ Open.*

Cont.

1. Continuing to care? Is National Health Service continuing healthcare supporting the people who need it in England?' Parkinson's UK, in association with the Continuing Healthcare Alliance, November 2016. https://goo.gl/0LNcAu

N.B. Additional articles on palliative care for people living with a neurological disease are noted in Media Watch 3 October 2016, #482 (pp.9-10).

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA (South Australian) | *The Australian* (Adelaide) – 17 November 2016 – **'South Australia euthanasia bill defeated by one vote.'** The nation's first euthanasia law at a state level has narrowly been defeated after Labor Speaker Michael Atkinson used a casting vote ... to end a marathon debate and vote against the historic bill in the South Australian parliament. The controversial bill – the state's 15th attempt to legalise voluntary euthanasia – had ... passed a second reading milestone with a 27-19 vote. The proposed legislation was then moved to a lengthy and complex debate, ending with a deadlocked conscience vote tied at 23 for and against. https://goo.gl/PFJWAq

Specialist Publications

Appropriate and inappropriate care in the last phase of life: An explorative study among patients and relatives

BMC HEALTH SERVICES | Online – 15 November 2016 – This study shows that patients and relatives interpret appropriate care in the last phase of life as a wide-ranging term, which can refer to supportive care, treatment decisions, location, the role of the patient's wish and patient-physician communication. These findings are in line with earlier studies, that showed that patients in the last phase of life have multiple and diverse care needs. The five dimensions of appropriate care are similar to, but broader than those identified in studies on good palliative care (PC). For instance, the domains described in the 'National Consensus Project Clinical Practice Guidelines for Quality Palliative Care'[1] mostly fall under the dimension "supportive care," while focusing little on treatment decisions and location. Apparently, patients and relatives perceive appropriate care in the last phase of life as broader than the presence of good quality PC. In many cases, inappropriate care could simply be defined as the absence or the opposite of appropriate care. In these cases, care was insufficient to meet the patients' and relatives' needs. However, the difference between appropriate care and inappropriate care was not always so clear-cut. While potentially curative or life-prolonging treatment was often described as inappropriate, there were also cases in which it was seen as appropriate. Accordingly, stopping potentially curative or life-prolonging treatment was described as appropriate as well as inappropriate (albeit less often). This illustrates how difficult decisions on starting, continuing or stopping potentially curative of life-prolonging treatment can be in advanced disease. Treatment can be appropriate by giving hope, a chance of prolonging life and it can be the patient's wish. But in many cases, treatment is more likely to lead to false expectations, side-effects and complications. https://goo.gl/VdQfa9

1. 'The National Consensus Project for Quality Palliative Care Clinical Practice Guidelines for Quality Palliative Care,' 3rd Edition 2013. https://goo.gl/5ichtT

Related

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 7 November 2016 – **'What have we got to lose?'** The literature regarding quality of care clearly lists chemotherapy and recurrent admissions in the few weeks before death as indicators of a job badly done, whereas use of palliative targeted therapy in the last month of life has raised the question of whether such treatment might compromise or delay appropriate palliative care near the end of life. And yet, the mythology around going down fighting remains omnipresent, a false ideal romanticized in the celluloid imagery of countless war movies and the commentary of losing football teams. https://goo.gl/82nnmO

Cont.

- *SOCIAL SCIENCE & MEDICINE* | Online – 9 November 2016 – '**Common or multiple futures for end-of-life care around the world? Ideas from the "waiting room of history."**' Around the world there is growing interest in the manner in which care is delivered to people at the end of life. However, there is little unanimity on what constitutes a "good death" and the appropriate societal responses to the issue of delivering culturally relevant and sustainable forms of end-of-life care in different settings are not subjects of broad agreement. The authors focus on the emerging narratives of global palliative care and offer an assessment of their implications. https://goo.gl/8wL1Jd

Using telehealth to support end-of-life care in the community: A feasibility study

BMC PALLIATIVE CARE | Online – 17 November 2016 – The trial showed that patients and carers[i.e., study participants] could manage the technology and provide data that would otherwise not have been available to the palliative care service. The average age of patients was 71.6 years... All 43 patients managed to enter data using the telehealth system. Self-reported data entered by patients and carers did identify changes in performance status leading to changes in care. Over 4,000 alerts were generated. Staff reported that video calls were similar (22.3%) or better/much better (65.2%) than phone calls and similar (63.1%) or better/much better (27.1%) than face-to-face. Issues with the volume of alerts generated, technical support required and the impact of service change were identified. https://goo.gl/9xHWYg

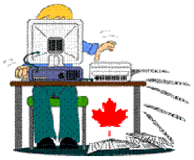
Selected articles on telehealth in the context of end-of-life care

- *BMC MEDICAL INFORMATICS & DECISION MAKING* | Online – 13 October 2016 – '"**Massive potential" or "safety risk"? Health worker views on telehealth in the care of older people and implications for successful normalization.**' In this study, rural health clinicians and residential aged care staff were enthusiastic about the potential of telehealth to enhance healthcare access for their clients. Experience and exposure to telehealth technology appeared to aid normalization, particularly among health workers providing services in less-rationed urban areas. https://goo.gl/YSYVx3

- *RURAL AND REMOTE HEALTH* | Online – 17 October 2016 – '**Telehealth services in rural and remote Australia: a systematic review of models of care and factors influencing success and sustainability.**' The authors identified a wide variety of telehealth services being provided in rural and remote areas of Australia. This review provides information for policy makers, governments and public and private health services that wish to integrate telehealth into routine practice and for telehealth providers to enhance the sustainability of their service. https://goo.gl/Gw4XST

Noted in Media Watch 21 September 2015, #428 (p.17):

- *TELEMEDICINE & E-HEALTH* | Online – 11 September 2015 – '**A systematic review of telehealth in palliative care: Caregiver outcomes.**' All the studies measuring caregiver quality of life showed no significant difference after telehealth interventions. The caregiver anxiety score decreased after the intervention in two studies, and one reported significantly reduced caregiver burden. Although feasibility of caregiver satisfaction with the telehealth intervention was not the focus of this review, most studies reported such findings. https://goo.gl/MOxIKc



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

End-of-life care in the U.K.

What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large U.K. city

BMJ OPEN | Online (In Press) – Accessed 19 November 2016 – For patients with advanced cancer, several randomised controlled trials have shown that access to palliative care (PC) at least 6 months before death can improve symptoms, reduce unplanned hospital admissions, minimize aggressive cancer treatments and enable patients to make choices about their end of life care (EOLC), including exercising the choice to die at home. This study determines in a U.K. population the duration of PC before death and explores influencing factors. This retrospective cohort study analysed referrals to three specialist PC services; a hospital based inpatient PC team, and two community based services (hospices). For each patient referred to any of the above services the authors identified the date of first referral to that team and calculated the median interval between first referral and death. They also calculated how referral time varied by age, sex, diagnosis and type of PC service. Median age of the sample [i.e., patient population studied] was 75 years. 84.0% patients had a diagnosis of cancer. Age, diagnosis and place of referral were significant predictors of duration of PC before death. Age was independently associated ... with duration of PC regardless of diagnosis. Patients over 75 years have 29 fewer days of PC than patients under 50. Patients with non-cancer diagnoses have 13 fewer days of PC than patients with cancer. Additionally, patients referred to hospital PC receive 24.5 fewer days PC than those referred to community PC services. The current timing of referral to PC may limit the benefits to patient in terms of improvements in EOLC, particularly for older patients and patients with conditions other than cancer. https://goo.gl/3WnIdH

Related

- *NURSING TIMES* | Online – 17 November 2016 – **'Most hospice care being given in community settings.'** Around 80% of hospice care for adults is provided in a range of community settings, with less than a fifth delivered in hospice inpatient units, according to new data analysis.[1] The findings ... provide the first ever snapshot of hospice care across the U.K. It shows that the majority of clinical care for adults is delivered in different community-based settings including people's homes, day hospice and hospice outpatient services. https://goo.gl/NS67lu

  1. 'Hospice care in the U.K. 2016: Scope, scale and opportunities,' Hospice UK, November 2016. https://goo.gl/6zaGkw

- *NURSING CHILDREN & YOUNG PEOPLE* | Online – 8 November 2016 – **'Partnership working between hospice and children's community nursing teams.'** This article describes the implementation and evaluation of a new partnership between a children's hospice service and a National Health Service children's community nursing team to support children's palliative care in the community. Findings demonstrate that it has offered significant support to children, and families valued the role of the new Alexander's nurse. https://goo.gl/nVW3we

Home and/or hospital: The architectures of end-of-life care

CHANGE OVER TIME, 2016;6(2):248-263. Examining the key texts that have been published on palliative care (PC) architecture, and focusing on the most important hospital and hospice design-research issues that have evolved since the 1980s, this paper highlights a significant inconsistency between those PC design developments and the design of PC units in recently constructed major hospitals. The architects of hospices, PC facilities, and the U.K.-based Maggie's Centres strive to make their buildings look like houses to express a collective environment of caring, emphasizing quality-of-life issues over medical efficiency. This reflects larger changes in the design of therapeutic landscapes since 1980, which endeavor to normalize illness and death by engaging architecture as a tool of distraction. However, as is evidenced by state-of-the art hospitals – a recently-opened, North American health care architecture consortium-designed, 517-bed healthcare center in Montreal, Canada, as well as several European hospitals – such design elements are often omitted from the design of new hospitals. https://goo.gl/1bFLGq

N.B. Additional articles on the architecturally design of hospices and palliative care facilities are noted in Media Watch 28 July 2014, #368 (p.13).

Wished for and avoided conversations with terminally ill individuals during final conversations

DEATH STUDIES | Online – 15 November 2016 – The current investigation examines retrospectively wished for and avoided conversations during the end of life with a deceased relational partner. Participants reported on conversations they wished they had engaged in and conversations that they intentionally avoided, as well as reasons why they did not engage in the conversations. Analyses revealed the following wished for and avoided conversations: 1) Negative relationship characteristics; 2) Death and dying; 3) Post-death arrangements; and, 4) Personal information. Furthermore, participants indicated the following reasons for not discussing the aforementioned topics during final conversations: 1) Emotional protection; 2) Relational differences; and, 3) Condition of the dying. Theoretical and practical implications for end-of-life communication are discussed. https://goo.gl/393xK9

Related

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(6):556-563. **'The "conversation nurse" model: An innovation to increase palliative care capacity.'** In collaboration with the Institute for Healthcare Improvement, Care New England's (Rhode Island) palliative care (PC) team developed the model of the "conversation nurse" – a nurse trained in conversations with patients and families about end-of-life care. The reach of a small PC team has been expanded by using "conversation nurses," allowing increased capacity to provide PC. https://goo.gl/OfNFBw

"Doing death"

Reflecting on the researcher's subjectivity and emotions

DEATH STUDIES | Online – 15 November 2016 – As death is a universal concept this paper adds to the literature by showing the problematic nature of the idea that a researcher must be objective when studying this topic. Thus this paper discusses the complexity of subjectivity within death studies. Three key elements of subjectivity form the basis of this discussion: 1) The researcher's cultural background; 2) The researcher's personal experiences; and, 3) The emotional impact of research on the researcher. It is argued that transparency about the subjective nature of death studies research can be fruitful in understanding the research process before, during and after fieldwork. https://goo.gl/ZDYqsk

Worth Repeating

'The culture of research in palliative care: "You probably think this song is about you"' (p.15), in *Journal of Palliative Medicine*.

Bereavement: An anthropological approach

DEATH STUDIES | Online – 15 November 2016 – The literature on bereavement has been dominated by psychology (Bowlby, 1969; Freud, 1961; Parkes, 1972; Worden, 1991). Social Science (Hockey *et al*, 2001; Klass, Silverman & Nickman, 1996; Valentine, 2008; Walter, 1999) has expanded that perspective by illustrating the ways in which the bereaved maintain continuing bonds with the deceased. In this article, the author builds upon the social science literature from an anthropological perspective. She focuses upon how the bereaved must learn to live in the social environment without the deceased in what she calls a "new normal." The connections to their social environment have been altered as a link in those connections has been broken. The bereavement process requires repairing that rupture and developing a new way in which to adopt a new sense of self. This article mainly focuses on issues involved with the loss of a spouse. https://goo.gl/1sgf45

Noted in Media Watch 14 November 2016, #487 (p.7):

- *END OF LIFE JOURNAL* | Online – 10 November 2016 – **'A walk through bereavement theory.'** 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. https://goo.gl/h2FTaA

End-of-life care in Hong Hong

Experiences of healthcare professionals in providing palliative end-of-life care to patients in emergency departments: a systematic review protocol

JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS, 2016;14(10):9-14. The emergency department (ED) is increasingly recognized as a potential site to provide palliative care (PC) to patients at their end of life. Although the true incidence of patients with these health needs in ED remains unknown, it is expected to increase over time as the population ages. As such, all healthcare professionals working in the ED are likely to be expected to provide this care. However, such provision of care in the ED setting is not without concerns. The practice in emergency care is characterized by managing acute health problems, making critical decisions under pressure and with limited time to discuss treatment plans and preferences with patients and their families. This ED culture may not be conducive to providing quality PC. Indeed, healthcare professionals report mixed feelings about providing this type of care in the ED setting. Given that the provision of PC is increasing and that it has significant implications for the practice and wellbeing of healthcare professionals working in the ED, understanding the caring experience from their perspectives will add to the body of knowledge in this area. https://goo.gl/sr9MC4

Noted in Media Watch, 2 May 2016, #460 (p.7):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 April 2016 – **'Effectiveness of emergency department based palliative care for adults with advanced disease: A systematic review.'** Emergency departments (EDs) are seeing more patients with palliative care (PC) needs, but evidence on best practice is scarce. There is yet no evidence ED-based PC affects patient outcomes except for indication from one study of no association with 90-day hospital readmission, but a possible reduction in length of stay if PC is introduced early at ED rather than after hospital admission. http://goo.gl/J18JG6

N.B. Additional articles on end-of-life care in the emergency department are noted in Media Watch 18 April 2016, #458 (p.10).

Physician well-being

The things we have lost

JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION, 2016;316(18):1871-1872. When most people consider the grief endured by physicians in training, they look first to the devastating narratives of patient care – sudden illness, agonizing decline, putrid decay, untimely death, haunting errors, and crushing uncertainty. Even more than a decade from residency, I am pierced by these tragic moments and faces – each still heart-shatteringly vivid. Recognizing the direct emotional toll of patient care, medical educators in some training programs have earmarked time for death rounds, Schwartz rounds, or narrative medicine sessions. Many of these interventions are deployed in high-intensity settings within the clinical learning environment where residents wrestle daily with ethical dilemmas or end-of-life dynamics. Where physician well-being is concerned, I offer that these curricular endeavors are a natural starting point, but may not represent a complete solution. https://goo.gl/7dAhDU

N.B. Additional articles on burnout and compassion fatigue among hospice and palliative care professionals are noted in the issues of Media Watch of 1 August 2016, #473 (p.7) and 9 November 2015, #435 (pp.13-14).

Quality of Physician Orders for Life-Sustaining Treatment (POLST) forms completed in nursing homes

JOURNAL OF PALLIATIVE MEDICINE | Online – 14 November 2016 – The authors completed POLST audits for 938 residents in 13 nursing homes in Los Angeles, California. They recorded whether POLST forms were signed by both the patient (or proxy) and the physician, and whether the patient's treatment choices regarding resuscitation and medical intervention were consistent, as required by the California form. Overall, 69.6% of audited POLST forms had at least one indicator of poor quality. Most lacked a required signature (15.8% lacked a physician signature and 17.4% lacked a patient/proxy signature) and 5.6% had conflicting treatment preferences. The authors found 30.4% of POLST forms for nursing home residents were not complete or documented clinically contradictory treatment preferences. Improvement in the quality of POLST forms is needed. https://goo.gl/O11gSe

Noted in Media Watch 7 November 2016, #486 (p.10):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 1 November 2016 – **'The quality of Physician Orders for Life-Sustaining Treatment (POLST) decisions: A pilot study.'** A majority (59%) of participants recognized the POLST form. Participants were generally accurate in their knowledge of how POLST orders guide treatment concerning cardiopulmonary resuscitation (CPR) (68%), antibiotics (74%), and artificial nutrition (79%), but less so for medical interventions (50%). Discordance between current preferences and POLST orders is complex. https://goo.gl/YNhUfU

Noted in Media Watch 19 October 2015, #432 (p.14):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 14 October 2015 – **'Toward evidence-based end-of-life care.'** More than two thirds of U.S. states have implemented Physician (or Medical) Orders for Life-Sustaining Treatment (POLST/MOLST) programs despite the absence of compelling evidence that they improve patient outcomes. http://goo.gl/9gFs4X

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 15 November 2016 – **'Factors influencing advance care planning among older adults in two socio-economically diverse living communities.'** Higher levels of knowledge and engagement in advance care planning (ACP) were reported at the high-income eligible community [studied] as compared to the affordable housing community [studied]. These findings provide insight into the influence of the contextual forces that encourage and support ACP. https://goo.gl/gOAH45

Elder care in Ireland

The prevalence of potentially abusive behaviours in family caregiving

MEDSCAPE | Online – 14 November 2016 – This is the first study to use a nationally representative sample to measure the extent to which family carers engage in behaviours that may be harmful to their older relative. Family carers frequently reported engaging in such behaviours, with psychologically "potential abusive behaviours" (PHBs) being more prevalent. Extrapolated to the national population of carers of older people receiving a carer's allowance, findings suggest that 9,000 carers engaged in behaviours that may be harmful to their older relative within the previous 3 months, with over 4,000 carers considered to be engaging in behaviours that may be equivalent to elder abuse. These findings are consistent with a systematic review of elder abuse studies which reported that the prevalence of abusive behaviours by family carers ranged from 11 to 55%. As the main providers of community care to older people, greater emphasis needs to be placed on adequately supporting family carers so that they can provide safe quality care to their older relatives. If PHBs can be detected earlier, interventions can be introduced to avert situations from deteriorating into serious cases of elder abuse. https://goo.gl/msk3ER

Cont.

Noted in Media Watch 13 December 2010, #179 (p.12, under 'Worth Repeating'):

- *JOURNAL OF PALLIATIVE MEDICINE*, 2006;9(1):127-136. **'Elder abuse at end of life.'** Patients at the end of life, by the nature of their clinical and social circumstances, are at high risk for elder abuse. Underreporting of elder abuse is a growing concern. The clinical presentation of abuse may overlap with the natural dying process, further compounding the problem. Multidisciplinary teams have been shown to be the effective intervention for assessment and prevention of abuse. http://goo.gl/dowcRr

End-of-life and palliative care of patients with drug and alcohol addiction

MENTAL HEALTH PRACTICES | Online – 9 November 2016 – This literature review attempted to identify current knowledge of the end of life (EOL) care needs of patients with drug and alcohol addiction, particularly in the U.K., and to identify any existing good practice guidance. Three themes emerged: first, the need to improve recognition of substance misuse in patients receiving palliative care (PC), and how to meet the pain management challenges PC teams face when caring for patients who have current or past opiate, benzodiazepine or alcohol addictions. Second, no U.K. published literature was found that directly addressed the subject of this literature review, but there were some U.S. sources that looked at a family systems approach to the care of dying substance misuse patients, and the role of social workers and methadone counsellors in the care of dying patients receiving opiate substitution treatment. Third, there is inequitable access to EOL and PC services for homeless people, many of whom experience addictions. The author recommends a discussion about what the term recovery can mean when applied to a person with addiction at the EOL, better recognition of approaching EOL in patients with drug and alcohol addictions and closer working relationships between PC and addictions services. https://goo.gl/A71TR2

Noted in Media Watch 29 August 2016, #477 (p.7):

- *BMJ SUPPORTIVE & PALLIATIVE CARE*, 2016;6(3):392-393. **'End-of-life care for people with alcohol and other drug problems: An exploratory study.'** The problematic use of substances is linked to many forms of chronic and life-threatening conditions, the majority of which affect people in later life. In part as a consequence of population ageing and with evidence suggesting that older people's substance use is increasing, this complex and heterogeneous group is growing. Thus greater numbers will require palliative care and present new challenges to end-of-life services. This study explores the nature and extent of these changes and the needs of service users and providers. http://goo.gl/EM7WcD

Unconscious dying: The lightly tilled soil of palliative care and psychodynamics

MORTALITY | Online – 14 November 2016 – It goes without saying death, and foreknowledge its inevitability, has always been the ultimate human challenge, that drives, at conscious and unconscious levels, everything that is done, thought and believed. Given the dominant worldview of logical positivism, scientific mastery and personal control, coupled with modern epidemiological realities, decision-making and care for people who are approaching death is a major challenge for society and health systems. For over 50 years the lead has been taken by the hospice/palliative care (PC) "social movement," and recently more broadly in health, especially in aged and intensive care, and by policy-makers. The overwhelming discourse and methodological approach tends to be linear, empirical and logical, in line with the zeitgeist, the "regimes of truth" and "evidence base" dominant in the system. This paper explores the possible unconscious personal and organisational forces at play when health services and society engage with the threat of death. It posits the view that a wider reticence to acknowledge the possibility of deep instinctual forces limits the capacity of the health system, its professional teams, individuals and wider society to work towards "healthier" relationships with death, the dying, the dead and ourselves as "mortally threatened" at all times. Concepts such as identification, projection, transference and "organisation in the mind" will be explored in the death, grief and PC context, as well as a notion of "ingestion" or "transmission" of pain and loss of others as a driver of organisational discord and burn out. https://goo.gl/iGgE0c

End-of-life care in Norway

GPs must be encouraged to play active role in palliative care

NEWS MEDICAL | Online – 16 November 2016 – Hospitals typically provide excellent end-of-life care for their patients. But when GPs assume responsibility for terminal patients, things don't always go so well. Perhaps the GP hasn't seen the patient for several years. Moreover, many GPs have very little experience of palliative care (PC). "In a survey that we've carried out, there are big differences between GPs who follow up and make home visits to terminal patients, and those who neglect this task entirely," says Line Melby at SINTEF [Stiftelsen for industriell og teknisk forskning – The Foundation for Scientific & Industrial Research]. Together with her colleagues, Melby has carried out an evaluation of the services offered to persons requiring palliative treatment. The research is being carried out for the Norwegian Directorate of Health. The issue of the benefits of dying at home has been investigated as part of the evaluation. Do health care professionals believe that this is what patients want? And has Norway facilitated the opportunity for a good death at home? The public authorities and voluntary organisations frequently make the point that ideally, people should be allowed to die at home. The SINTEF survey revealed that, on the contrary, many thought that the aim of facilitating death at home will place great demands on healthcare professionals, next-of-kin and the municipal healthcare services. One respondent from a PC home unit said that he "believed that patients live with the idea of preferring to die at home, but only before they arrive here," referring to the fact that in his experience many people felt insecure at home. "Very few people in Norway die at home, and we are some way behind other countries such as The Netherlands, where it is common for people to be born and die at home," says Melby. "Norway is more institution-based than other countries, and even the elderly are for the most part in work. Our family and community structures are different. There has been a lot of discussion on this topic, but in our study the majority of respondents felt that death at home should not be an aim in itself..." she says. https://goo.gl/Hdp5o4

Noted in Media Watch 29 August 2016, #477 (p.6):

- *BMC PALLIATIVE CARE* | Online – 24 August 2016 – **'Patients' perceptions of palliative care quality in hospice inpatient care, hospice day care, palliative units in nursing homes, and home care: A cross-sectional study.'** In Norway, palliative care (PC) is provided by a public healthcare system in primary or community care (CC), and specialist healthcare (SH) contexts (tertiary and secondary care). CC and SH provide non-specialized PC ... as an integrated part of the services, in addition specialized PC services are offered. http://goo.gl/sENwle

Noted in Media Watch 6 July 2015, #417 (p.12):

- *OPEN JOURNAL OF NURSING*, 2015;5(6):538-547. **'To die at home or to end life in an institution.'** This study aimed to determine the main causes for the low proportion of deaths at home in Norway. A retrospective cohort study was conducted in six municipalities. This study showed how challenging it is for the family and health personnel in the last steps of life. However, when physical distress is under control, and when a dying patient and his/her significant other genuinely wish for death at home, it is necessary to control physical distress. http://goo.gl/03lz5J

Related

- *JOURNAL OF THE AMERICAN BOARD OF FAMILY MEDICINE*, 2016;29(6):748-758. **'Perspectives of primary care providers toward palliative care for their patients.'** The authors explore primary care providers' willingness and perceived capacity to provide basic palliative care (PC), and their concerns and perceived barriers. They identified three major themes: 1) Participants recognize palliative needs in patients with complex problems; 2) They reactively respond to those needs using practice and community resources, believing that meeting those needs at a basic level is within the scope of primary care; and, 3) They can identify opportunities to improve the delivery of a basic palliative approach in primary care through practice change and redesign strategies used in enhanced primary care environments. Systematic attention along the multidimensional domains of basic PC might allow practices to address unmet needs in patients with complex illnesses by using existing practice improvement models, strategies, and prioritization. https://goo.gl/LIG4F5

Cont.

- *JOURNAL OF NURSE PRACTITIONERS* | Online – 9 November 2016 – **'Primary palliative care for every nurse practitioner.'** The ability to provide primary palliative care (PC) is a skill set that nurse practitioners should acquire, develop, and refine. The relief of suffering – physical, emotional, and spiritual – leads to improved patient outcomes and higher patient satisfaction. Primary PC skills include thorough and effective symptom assessment and management, initiating and guiding conversations around advance care planning, and completing medical directives that guide care with life-limiting/life-threatening illness. https://goo.gl/kVWOXA

High-fidelity simulation: Teaching end-of-life care

NURSING EDUCATION TODAY | Online – 11 November 2016 – The American Nurses Association, American Association of Colleges of Nursing, and the Institute of Medicine of the National Academies are unified in the position that nursing education must prepare students to coordinate and perform end-of-life (EOL) care. Yet, according to literature, undergraduate nursing education in EOL care remains inadequate. Following a review of literature indicating a need for more EOL instruction, a high-fidelity simulation activity is introduced and described. Included are guidelines for preparation, role assignment, integration of other professionals and family, and student reflection after the activity. Student evaluations indicate that the simulation is valuable and improves self-efficacy in caring for the dying. By providing students with the opportunity to experience EOL in a low-risk, learning environment, a high-fidelity EOL simulation activity can help educators bridge the knowledge gap in nursing education. https://goo.gl/wlZDas

Palliative care in obstetrics and gynecology

OBSTETRICS & GYNECOLOGY | Online – 3 November 2016 – Obstetrics and gynecology patients for whom palliative care (PC) is most appropriate include women with gynecologic cancer and women with a fetus or neonate with a potentially life-limiting illness. Integration of PC for these patients offers both clinical and health care utilization benefits, including improved symptom management, improved quality of life, and high-value care. PC can be provided by PC specialists ... or by the team treating the life-limiting illness, depending on the complexity of the need. Health care providers caring for patients with life-limiting illness, including obstetrician-gynecologists, must possess a basic primary PC skill set, including symptom management for common symptoms such as pain and nausea and communication skills such as breaking bad news. This skill set must be taught and evaluated during training and used consistently in practice to ensure that our patients receive truly comprehensive care. https://goo.gl/pUvhwg

Breaking bad news to patients with cancer: A randomized control trial of a brief communication skills training module incorporating the stories and preferences of actual patients

PATIENT EDUCATION & COUNSELING | Online – 13 November 2016 – The authors interviewed patients with cancer to learn about their communication experiences. They created/tested a breaking bad news (BBN) communication skills training module. The brief training module used video-recorded segments from the patient interviews. Intervention group students and residents significantly improved their BBN skills. Implementation of this brief individualized training module within health education programs could lead to improved communication skills and patient care. https://goo.gl/09vkI4

Noted in Media Watch 7 November 2016, #486 (p.11):

- *PALLIATIVE & SUPPORTIVE CARE* | Online – 2 November 2016 – **'Factors associated with patient preferences for communication of bad news.'** This study aimed to explore the demographic, medical, and psychological factors associated with patient preferences with regard to communication of bad news. Outpatients with a variety of cancers were consecutively invited to participate ... after their follow-up medical visit. A questionnaire assessed their preferences regarding the communication of bad news, covering four factors: 1) How bad news is delivered; 2) Reassurance and emotional support; 3) Additional information; and, 4) setting – as well as on demographic, medical, and psychosocial factors. https://goo.gl/Rd4CjX

Cont.

Noted in Media Watch 4 July 2016, #469 (p.3):

- U.S. | *The New York Times* – 1 July 2016 – **'What doctors know about how bad it is, and won't say.'** Experts have repeatedly urged doctors to talk about the elephants in the room, especially at the end of life. But two recent studies show how achingly slow progress has been.[1,2] Even terminally ill patients still receive scant information, researchers have found, while family members acting for ICU patients commonly contend with confusion and misinformation. The studies uncover some reasons for the disconnect. Doctors, it seems, shouldn't get all the blame. http://goo.gl/sXnslm

    1. 'Discussions of life expectancy and changes in illness understanding in patients with advanced cancer,' *Journal of Clinical Oncology*, 23 May 2016. [Noted in Media Watch 30 May 2016, #464 (p.3)] http://goo.gl/K2szxn

    2. 'Prevalence of and factors related to discordance about prognosis between physicians and surrogate decision makers of critically ill patients,' *Journal of the American Medical Association*, 2016;315(19): 2086-2094. [Noted in Media Watch 23 May 2016, #463 (p.4)] http://goo.gl/VG6Xf3

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *ANNALS OF INTERNAL MEDICINE* | Online – 15 November 2016 – **'The annals of medical assistance in dying.'** In the annals of assisted death, 2016 was Canada's watershed year. On 17 June, a new law permitting the practice of euthanasia and assisted suicide, or medical assistance in dying (MAID), received royal assent. The advent of this law concluded an intense process of inquiry and debate in the maelstroms of parliament and public opinion. Among the handful of nations that permit any form of euthanasia or assisted suicide, Canada had a unique catalyst for initiation of a controversial policy shift: a firm decision in February 2015 by the Supreme Court of Canada that overturned a legal precedent established by the same court two decades earlier. https://goo.gl/5sRh9U

Cont. next page

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.

- *THE GERONTOLOGIST*, 2016;56(6):1072-1081. **'Older people's discourses about euthanasia and assisted suicide: A Foucauldian exploration.'** The [study] participants presented a "confused and conflicted" discourse, expressing the view that euthanasia/assisted suicide (EU/AS) is a family affair, whilst also articulating a strong sense of self-determination. Although a discourse of the medicalization of dying through medical control and surveillance was endorsed, an alternative discourse of "dying outside the medical gaze" emerged. Participants, who were in favor of EU/AS, felt "voiceless," as apparent double standards were applied in the debate, and powerful others, for example, physicians and politicians, seemed reluctant to engage. Within an "aged death" discourse, the anticipated dependency on poor care from (professional) others, made participants consider EU/AS as ways of avoiding this stage of life and the associated loss of dignity. https://goo.gl/FqhM40

Worth Repeating

Commentary

The culture of research in palliative care: "You probably think this song is about you"

JOURNAL OF PALLIATIVE MEDICINE, 2009;12(3):215-217. "But is it right?" If my memory can be trusted, the question came after a presentation by Eduardo Bruera on the importance of research in palliative care (PC). The nurse asking this question ... did so, not in a way that felt dismissive or punitive, but rather, with a sense of genuine caring and concern. After all, people approaching death have limited time and energy; did we really want to be asking them, indeed, was it right to be asking them to expend effort in answering our research questions? Many have argued that the terminally ill are vulnerable and ought to be protected from enrollment in research studies given they are unlikely to realize any advantage in return for their loss of time and energy. I clearly remember Dr. Bruera's response. In essence, he asked if the *status quo* was worth defending. In other words, were we convinced that the quality of care, the efficacy of treatment and the completeness of knowledge underpinning PC were beyond reproach or the possibility of improvement? If so, there was neither justification nor cause to proceed. On the other hand, if care for the dying is less than optimal ... how can we morally justify not doing palliative care research? [Noted in Media Watch 9 March 2009, #87 (p.9)] https://goo.gl/KKhdFT

Media Watch: Online

International

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

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/lOSNC7

Cont.

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