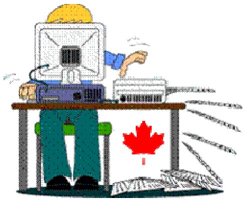
Media Watch...

*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.*

2 May 2016 Edition | Issue #460



Compiled & Annotated by Barry R. Ashpole

In the approach to end of life: Scroll down to Specialist Publications and 'Dying is the most grown-up thing we ever do: But do health care professionals prevent us from taking it seriously?' (p.5), in *Health Care Analysis*.'

Canada

Fixing healthcare in prisons will save us all money

ONTARIO | *The Globe & Mail* – 20 April 2016 – There are a lot of people in Canada's jails and prisons, and many are among the unhealthiest in society.[1] There are about 140,000 criminal offenders under supervision at any given time, including 25,000 incarcerated in provincial and territorial jails and another 15,000 in federal penitentiaries. Consider that, among men sentenced to federal penitentiary (meaning sentences of two years or more): 80% have a serious substance-abuse problem; 64% are overweight or obese; 34% have suffered a traumatic brain injury; 25% have a diagnosed mental illness; 28% have hepatitis C; 20% have a cardiovascular condition; 16% have latent tuberculosis; 15% have a respiratory illness; 14% have asthma; 6% have diabetes; and, 1.2% have HIV-AIDS (about 10 times the national average); life expectancy of inmates is about 15 years less than the general population. And so on and so forth. Incarceration should not solely be about punishment, but rehabilitation. A stint in the slammer is a prime opportunity to get people the help they need – not only for compassionate reasons, but because early intervention has the potential to save significant healthcare dollars down the road. Yet the reality is quite different: The healthcare we provide in correctional facilities is often non-existent and routinely abysmal. http://goo.gl/YUVsZW

1. 'Fractured Care: Public Health Opportunities in Ontario's Correctional Institutions,' John Howard Society, 2016. http://goo.gl/jfk5rE

N.B. No mention is made of end-of-life care.***BRA***

Specialist Publications

'Integrating correctional and community health care: An innovative approach for clinical learning in a baccalaureate nursing program' (p.9), in *Nursing Forum.*

Prison Hospice: Backgrounder

End-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of articles, reports, etc., on the subject noted in past issues of the weekly report can be downloaded at the Palliative Care Community Network website: http://goo.gl/qgd4hp

Cont.

Noted in Media Watch, 14 April 2014, #353 (p.2):

- ONTARIO | *The Toronto Star* – 6 April 2014 – **'Chaplain Dan Haley's house of forgiveness.'** Ronald Gourgon stabbed a man in the chest and was sentenced for murder... Now walking with a cane, the 67-year-old has a deteriorating valve in his heart and not much longer to live. Recently paroled from an Ontario prison, he called on Dan Haley, a chaplain in Peterborough, who runs a supportive housing centre that offers palliative care for ex-inmates.[1] http://goo.gl/BVXOxt

  1. Peterborough Community Chaplaincy ('The Final Transition'): http://goo.gl/k25QLW

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CBC NEWS | Online – 25 April 2016 – **'"We don't play God": Indigenous communities concerned about doctor-assisted suicide.'** A Dene leader says doctor-assisted suicide is not part of Aboriginal culture and he's calling on the federal government to consult with Indigenous people before passing new legislation. Francois Paulette, chair of Yellowknife's Stanton Territorial Health Authority Elders' Advisory Council, says Indigenous people are bound by spiritual law, not man-made law. The president of the Indigenous Physicians Association agrees that more consultation is needed about how physician-assisted dying will be delivered in remote and Indigenous communities. http://goo.gl/WQWg9w

- THE CANADIAN PRESS | Online – 24 April 2016 – **'Medical schools preparing to teach future doctors about assisted death.'** With physician-assisted death soon to forever alter the face of medicine, Canada's medical schools are under pressure to decide at what point in the curriculum future doctors should be introduced to this paradigm shift – and what that teaching needs to entail. While some of the universities that train the next generation of doctors have begun preparations to add assisted dying to their curricula, many have been taking a wait-and-see attitude... Anthea Lafreniere, a fourth-year medical student at the University of Ottawa, who will soon add MD after her name, said that as part of second-year courses, students take part in 'Palliative Week,' when they are introduced to concepts around end-of-life care. http://goo.gl/N83UKy

U.S.A.

Feds propose docking or rewarding Medicare doctors for quality

USA TODAY | Online – 27 April 2016 – Federal regulators proposed a rule ... that will adjust hundreds of thousands of physicians' Medicare payments to reward or penalize them based on how healthy they keep their patients. The announcement by the Department of Health & Human Services (HHS) comes a year after Congress passed a law that was known as the "doc fix" bill and prevented a huge cut in Medicare payments. It also authorized HHS to come up with more streamlined ways of paying doctors that emphasize quality over quantity of services. The announcement is not just another incremental development associated with the Affordable Care Act's mission to reverse the health care system's tendency to authorize unnecessary tests and procedures. Unlike much of healthcare, the "doc fix" bill was supported by a bi-partisan majority along with patient groups and medical associations. http://goo.gl/UkhVlh

Specialist Publications

'Effect of ownership on hospice service use: 2005-2011' (p.9), in *Journal of the American Geriatrics Society.*

'Exploring barriers among primary care providers in referring patients to hospice' (p.9), in *Journal of Hospice & Palliative Nursing.*

'Economic impact of an advanced illness consultation program within a Medicare Advantage Plan population' (p.9), in *Journal of Palliative Medicine.*

'End-of-life care intensity and hospice use: A regional-level analysis' (p.8), in *Medical Care.*

International

End-of-life care in England

Cancer charity warns of "meltdown" in care for dying patients

U.K. (England) | The Press Association – 27 April 2016 – End-of-life care (EOLC) in England is heading for a "meltdown," a leading cancer charity has warned. Many dying patients are not getting proper pain relief, they are not being involved in key decisions about their care, and many are unable to die at home, Macmillan Cancer Support said. The charity said that growing demand for EOLC will put an "intolerable" strain on the National Health Service and social services. It has estimated that by 2020 there will be around 144,000 people a year in England dying from cancer – which equates to one person every four minutes. The figure also represents an additional 15,000 cancer deaths compared with 2010. The estimate, based on population projections and cancer trends, highlights an " urgent need" to tackle the country's approach to EOLC. Commenting on Macmillan's estimates, Simon Chapman, director of policy and external affairs at the National Council for Palliative Care, said: "Although the majority of people die from conditions other than cancer, people with cancer are more likely to be able to access palliative and EOLC than others." Figures released last week revealed that some people in their final days of life are not getting enough help to eat or drink and are dying in pain.[1] http://goo.gl/Fmf3dk

Judge to decide treatment of two-year-old disabled boy who "no longer giggles"

U.K. (England) | *The Independent* – 27 April 2016 – Specialists have told a High Court judge that their treatment of a "profoundly neurologically disabled" two-year-old boy who they say no longer giggles when tickled and is "largely unresponsive" should be limited to palliative care (PC). Doctors want a ruling that limiting treatment to PC would be lawful and in the boy's best interests. They say further "invasive" life-saving procedures will distress him and be of little or no therapeutic benefit. But the youngster's parents – who say their son enjoys being cuddled – object. Mrs. Justice Parker is analysing the dispute at a public hearing in the Family Division of the High Court in London. She is not expected to make rulings until at least next month. The judge has said the youngster cannot be identified and no-one involved in the case named. http://goo.gl/rAOEK9

1. 'National Survey of Bereaved People (VOICES): 2015,' Statistical Bulletin, Office for National Statistics, April 2016. [Noted in Media Watch, 25 April 2016, #459 (p.9)] https://goo.gl/xJNHnB

Elder care in England & Wales

Care home insolvencies increase as sector pushed to "breaking point"

U.K. (England & Wales) | LocalGov.com – 25 April 2016 – New research ... [has] ... discovered 47 care home operators in England and Wales became insolvent last year, up from 40 the previous year. It also revealed the number of care home businesses becoming insolvent has risen by 34% over three years. The insolvencies are the result of the decline in council spending on care homes. There will be a £2.9 billion annual funding gap in social care by the end of the decade ... partly the result of the U.K.'s aging population, which is predicted to rise by 12% ... between 2015 and 2020. http://goo.gl/cpuK8v

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | *The Netherlands Times* (Amsterdam) – 27 April 2016 – **'Euthanasia cases rise 4% in 2015.'** A total of 5,516 people died by euthanasia in 2015, according to the annual report by the five regional euthanasia review committees... The most common reason for euthanasia to be requested was cancer. The number of granted euthanasia requests due to dementia increased from 81 in 2014 to 109 last year. And the number of requests granted due to another end-stage psychiatric disorder increased from 41 to 56. There were four cases where the review committees believe the doctors involved acted negligently. http://goo.gl/4MVYXF

Specialist Publications (e.g., in-print and online journal articles, reports, etc.)

The importance of early involvement of paediatric palliative care for patients with severe congenital heart disease

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 21 April 2016 – The authors discuss the advantages of a fully integrated palliative care (PC) ethos in patients with congenital heart disease, offering the potential for improved symptom control, more informed decision-making and enhanced support for patients and their families throughout their disease trajectory. These core principles may be delivered alongside expert cardiac care via non-specialists within pre-existing networks or via specialists in paediatric PC when appropriate. By broaching these complex issues early – even from the point of diagnosis – an individualised set of values can be established around not just end of life but also quality of life decisions, with clear benefits for patients and their families regardless of outcome. http://goo.gl/d0ylvT

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 26 April 2016 – **'Evaluating hospice and palliative medicine education in pediatric training programs.'** The authors surveyed all 486 Accreditation Council for Graduate Medical Education accredited pediatric training program directors (PDs) – 200 in general pediatrics, 57 in cardiology, 64 in critical care medicine, 69 in hematology-oncology and 96 in neonatology. They collected training program's demographics, PDs' attitudes and educational practices regarding hospice and palliative medicine (HPM). While most programs report perceived benefit from HPM training, there remains a paucity of opportunities for pediatric trainees. http://goo.gl/XHbgd6

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(2):139-148. **'Discovering the strength of parents whose children are at end of life.'** Eleven themes emerged from the data, with a subtheme of "the child" who was dying. Spirituality emerged as the most important strength, with positive attitude and finding meaning rating second. Results revealed the key strengths of parent caregivers, and the Strengths Guide was found to be an effective intervention for palliative/hospice care providers to assist parents to build on their strengths. http://goo.gl/9zn6BD

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 April 2016 – **'"Don't try to cover the sky with your hands": Parents' experiences with prognosis communication about their children with advanced cancer.'** Although most parents [i.e., study participants] ... found prognostic information upsetting, most also valued honest communication about prognosis... They noted that frank disclosure fostered hope by relieving uncertainty and allowing them to make the best possible decisions for their children. Excessive optimism or a lack of information, in contrast, was sometimes experienced as a threat to hope and the parent-clinician relationship. A minority of parents were upset by clinician communication about prognosis ... but most did not consider the clinician responsible for their distress. Rather, parents attributed distress to the difficult situation. http://goo.gl/d5fyWs

- *ZEITSCHRIFT FÜR GEBURTSHILFE UND NEONATOLOGIE*, 2016;220(2):53-57. **'Palliative care in the delivery room.'** Palliative care (PC) in the delivery room is a multi-professional challenge directed to the dying newborn and the parents as well as to the caregivers. Clinical experience shows that many aspects regarding this unique PC situation are not well known and cause relevant emotional distress to the health care providers. In this article basic background information of PC of newborns in the delivery room are presented. Recommendations are given focusing on: 1) Non-pharmacological and pharmacological ways of symptom control in PC of dying newborns; and 2) Meeting the individual psychological, emotional and spiritual needs of the parents. http://goo.gl/gcgnAC

  N.B. German language article.

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.

End-of-life care in Australia

Health service use and costs in the last 6 months of life in elderly decedents with a history of cancer: A comprehensive analysis from a health payer perspective

BRITISH JOURNAL OF CANCER | Online – 26 April 2016 – Those who died from cancer had significantly higher rates of hospitalisations and medicine use, but lower rates of emergency department use than those who died from non-cancer causes. Overall health care costs were significantly higher in those who died from cancer than those dying from other causes; and, 40% of costs were expended in the last month of life. The authors analysed health services use and costs from a payer perspective, and highlight important differences in patterns of care by cause of death in patients with a cancer history. In particular, there are growing numbers of highly complex patients approaching the end of life and the heterogeneity of these populations may present challenges for effective health service delivery. http://goo.gl/KeZKe6

Hope dies last … A qualitative study into the meaning of hope for people with cancer in the palliative phase

EUROPEAN JOURNAL OF CANCER CARE | Online – 21 April 2016 – Palliative patients may have strong hope, even hope for a cure, despite knowing their prognosis. Health professionals do not always understand patients who have this kind of hope. The meaning of hope is related to the importance of the object it is attached to, rather than to a real chance of achieving this object. Hope has a dual function: patients hope because they cannot forsake it and because they benefit so much from it. Hope can spring from many sources and is influenced by various factors. If there are fewer potent sources to tap into, people create hope themselves and this type of self-created hope takes more effort to maintain. Patients use different strategies to increase their hope, described as the "the work of hope." A better understanding of the work of hope can lead to better psychosocial support by health professionals. Health professionals convey many messages that affect the work of hope. http://goo.gl/gixJE3

Noted in Media Watch, 1 February 2016, #447 (p.12):

- *HUISARTS EN WETENSCHAP*, 2016;59(1):14-16. '**Managing hope in palliative care.**' Hope is important to people receiving palliative care, but it can put general practitioners in an awkward situation, especially when the patient has false hope. Patients and their caregivers approach the concept of "hope" not only from a realistic perspective, but also from a functional perspective (hope helps to cope with the situation) or a narrative perspective (hope fits with someone's narrative). http://goo.gl/QxcjeO

  N.B. Dutch language article.

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 January 2016 – '**Hope, symptoms, and palliative care: Do symptoms influence hope?**' Anxiety, depression, fatigue, and pain are reported to impair hope. The objective of this study was to determine whether age, gender, marital status, duration of cancer, symptoms, or symptom burden correlated with hope... This study found a correlation between symptom burden and hope was not clinically relevant, but was so for depression. http://goo.gl/zj7Mki

Dying is the most grown-up thing we ever do: But do health care professionals prevent us from taking it seriously?

HEALTH CARE ANALYSIS | Online – 23 April 2016 – This paper takes a somewhat slant perspective on flourishing and care in the context of suffering, death and dying, arguing that care in this context consists principally of "acts of work and courage that enable flourishing." Starting with the perception that individuals, society and health care professionals have become dulled to death and the process of dying in Western advanced health systems, it suggests that for flourishing to occur, both of these aspects of life need to be faced more directly. The last days of life need to be "undulled." Reflections upon the experiences of the author as carer and daughter in the face of her mother's experience of death are used as basis for making suggestions about how care systems and professionals might better assist people in dealing with "the most grown up thing" humans ever do, which is to die. http://goo.gl/i8c2Kr

<u>**End-of-life care in the U.K.**</u>

Supporting older people with cancer and life-limiting conditions dying at home: A qualitative study of patient and family caregiver experiences of Hospice at Home care

JOURNAL OF ADVANCED NURSING | Online – 26 April 2016 – This study provides additional insights as to the value of a Hospice at Home service where hospice nurses are helping to bring hospice-standard care into the home. This holistic care is clearly supporting the patient and older caregivers to live as well as they can, helping to promote and achieve the option of remaining in their home. The prospective study design enabled the authors to obtain the real-time experience of the participants, including the voices of the terminally ill who are often a forgotten population in research studies. http://goo.gl/BYUBEs

Meeting the needs of the growing very old population: Policy implications for a global challenge

JOURNAL OF AGING & SOCIAL POLICY | Online – 25 April 2016 – The authors outline several promising approaches for policy makers and professionals to develop evidence-based policies and programs that are tailored to the needs of very old adults and their families. They focus their discussion on three key topics essential to life care: the importance of integrated care to meet the complex care needs of the very old; the balance between formal and informal care; and, the development of suitable places for living. Besides more specific measures, the authors propose that policies which promote the social integration of very old adults in their communities would be particularly helpful, as these may benefit not only the very old and their families, but individuals of all ages. They conclude that the development of suitable policies addressing the needs of the very old will benefit from future investigation of cross-cultural similarities and differences in centenarians' characteristics, available services, as well as life conditions they encounter in communities and institutional contexts. http://goo.gl/v2wBsi

Noted in Media Watch, 28 March 2016, #455 (p.6):

- *AGE & AGING* | Online – 24 March 2016 – **'A good death for the oldest old.'** People aged over 85 are the fastest growing segment of the population, both in the U.K. and across all high-income countries. This is also the group of people who are most likely to die. So it is pertinent to consider how we can ensure that for the oldest old, their deaths, as well as their lives, are as good as we can help them to be. http://goo.gl/jmj0yG

N.B. Noted in the 11 April 2016 issue of Media Watch (#457, p.6) 'Death and the oldest old: Attitudes and preferences for end-of-life care: Qualitative research within a population-based cohort study,' PLOS One, 5 April 2016. http://goo.gl/UFaCvc

Developing triggers for the surgical intensive care unit for palliative care integration

JOURNAL OF CRITICAL CARE (World Federation of Societies of Intensive & Critical Care Medicine) | Online – 22 April 2015 – Despite the growing acceptance of palliative care (PC) as a component of high-quality care for patients with serious illness, it remains underutilized in the surgical critical care setting. This article provides insight into a model for PC integration into the surgical intensive care unit (SICU), utilizing triggers. Factors significantly associated with hospital death or hospice discharge were, repeat SICU admission, metastatic/advanced cancer, SICU physician referral, and the matching of two or more secondary criteria. A series of triggers can help identify patients who may benefit from PC consultation. http://goo.gl/TlsEnz

Noted in Media Watch, 25 November 2013, #333 (p.7):

- *AMERICAN JOURNAL OF RESPIRATORY & CRITICAL CARE MEDICINE* | Online – 21 November 2013 – **'Estimates of the need for palliative care consultation across U.S. ICUs using a trigger-based model.'** In this study approximately one in seven ICU admissions met triggers for palliative care consultation using a single set of triggers, with an upper estimate of one in five patients using multiple sets of triggers; these estimates were consistent across different types of ICUs and individual units. http://goo.gl/oRY1RQ

Cont.

Related

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(2):115-123. **'Nursing and end-of-life care in the intensive care unit: A qualitative systematic review.'** Three super-ordinate themes emerged: 1) The nurse on the intensive care unit (ICU): understanding how emotional burden, coping with death, and the nurse's role in the decision-making process may influence end-of-life care (EOLC); 2) EOLC for the critically ill patient: influenced by the presence of academic, health care, and environmental barriers and by facilitators such as communication with the family; and, 3) The role of the family within the ICU: the second priority in the care process, although a potential source of stress. http://goo.gl/x936m9

End-of-life care in Canada

Dying in hospital: Characteristics of end-of-life referrals to a palliative care consult team in an academic medical centre

JOURNAL OF HOSPICE & PALLIATIVE NURSING (Hospice & Palliative Nursing Association), 2016; 18(2):149-159. The purpose of this retrospective 4-year study was to examine the palliative care (PC) consult team database for demographic characteristics of patients specifically referred for end-of-life care (EOLC) at a large academic center affiliated with a regional cancer center. Study data support the statistic that many Canadians die in acute care hospital settings. The majority of patients referred for EOLC were elderly and equally likely to have a malignant or non-malignant diagnosis. These rapidly growing populations will only continue to expand over time. Given that the demand for PC services will eventually exceed supply, examining demographic trends is a key component required to better understand and plan across the PC service, the institution, and the health care system. http://goo.gl/y2wO3S

Interprofessional silence at the end of life: Do Swiss General Practitioners and hospital physicians sufficiently share information about their patients?

JOURNAL OF PALLIATIVE MEDICINE | Online – 28 April 2016 – GPs [i.e., study participants] described the quality of collaboration with hospital physicians as poor, in particular the lack of communication. Two main issues emerged: first, infrequent communication with HPs could negatively affect the care of the patient; second, GPs were concerned with the lack of information about hospital care and involvement in medical decision making given their longstanding relationships with their patients. http://goo.gl/w1ipmy

Effectiveness of emergency department based palliative care for adults with advanced disease: A systematic review

JOURNAL OF PALLIATIVE MEDICINE | Online – 26 April 2016 – Emergency departments (EDs) are seeing more patients with palliative care (PC) needs, but evidence on best practice is scarce. Five studies ... were included: three case series and two cohort studies. Interventions included a screening tool, traditional ED-PC, and integrated ED-PC. Two studies reported on hospital admissions: in one there was no statistically significant difference in 90-day readmission rates between patients who initiated integrated PC at the ED ... compared to those who initiated PC after hospital admission ... another study showed a high admission rate (90%) in 14 months following ED-PC, but without comparison. One study showed a length of stay (LOS) reduction... There was scarce evidence on other outcomes except for conflicting findings on survival: in one study, ED-PC patients were more likely to experience an interval between ED presentation and death ... another showed increased mortality risk in the intervention group; and, a case series described a higher in-hospital death rate when PC was ED-initiated (62%), compared to ward (16%) or ICU (50%)... There is yet no evidence that 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 LOS if integrated PC is introduced early at ED rather than after hospital admission. http://goo.gl/J18JG6

N.B. Listed in the 18 April 2016 issue of Media Watch (#458, p.10) are selected articles on palliative care in the emergency department.

Surgeons' perspectives on avoiding non-beneficial treatments in seriously ill older patients with surgical emergencies: A qualitative study

JOURNAL OF PALLIATIVE MEDICINE | Online – 22 April 2016 – Little is known about how surgeons formulate treatment decisions to avoid non-beneficial surgery, or engage in preoperative conversations about end-of-life (EOL) care. Twenty-four surgeons were interviewed. Participants felt responsible for conducting EOL conversations with seriously ill older patients and their families before surgery to prevent non-beneficial treatments. However, wide differences in prognostic estimates among surgeons, inadequate data about postoperative quality of life, patients and surrogates who were unprepared for EOL conversations, variation in perceptions about the role of palliative care, and time constraints are contributors to surgeons providing non-beneficial operations. Surgeons reported performing operations they knew would not benefit the patient to give the family time to come to terms with the patient's demise. Emergency general surgeons feel responsible for having preoperative discussions about EOL care with seriously ill older patients to avoid non-beneficial surgery. However, surgeons identified multiple factors that undermine adequate communication and lead to non-beneficial surgery. http://goo.gl/kNrt2N

Noted in Media Watch, 16 February 2015, #397 (p.11):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 11 February 2015 – **'The role of a do-not-escalate-treatment order.'** The authors illustrate the common problem of a surrogate decision maker psychologically distressed over the medical team's recommendation to withdraw life-sustaining treatment. They suggest how a do-not-escalate-treatment order can be helpful in such situations when the usual approaches to withholding or withdrawing care are not acceptable to the surrogate. http://goo.gl/wutYrz

A duty of kindness

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE | Online – 26 April 2016 – "When I can think of nothing positive to write about in a reference for a junior doctor, I say she is kind," commented a colleague. Kindness has now been relegated to an attribute of losers rather than being an integral part of a doctor's duty to a patient. Because our medical culture does not consistently support the practice of kindness, doctors may view kindness as "nice," but not an essential part of their practice. The Francis Report contained harrowing examples of unkindness to patients and failings in basic patient care.[1] Medicine's positivist view, prioritising technical progress, evidence-based medicine and targets, risks viewing a patient solely as an object of intellectual interest. Respecting a patient's dignity now involves pathways, guidelines and risk assessments. The technical and scientific elements of medicine outweigh psychosocial care which is sometimes thought of as part of an outdated "nostalgic professionalism." http://goo.gl/VXQph7

1. 'Report of the Mid-Staffordshire National Health Service Foundation Trust Public Inquiry,' February 2013. [Noted in Media Watch, 11 February 2013, #292 (p.5)] http://goo.gl/XPLTU

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

End-of-life care intensity and hospice use: A regional-level analysis

MEDICAL CARE (American Public Health Association, Medical Care Section) | Online – 22 April 2016 – Despite increased hospice use over the last decade, end-of-life care (EOLC) intensity continues to increase. To understand this puzzle, the authors sought to examine regional variation in intensive EOLC and determine its associations with hospice use patterns. EOLC intensity and hospice use patterns varied substantially across hospital referral regions (HRRs). Regional-level EOLC intensity was positively correlated with very short hospice enrollment. Comparing HRRs in the highest versus the lowest quintiles of intensity in EOLC, regions with more intensive care had higher rates of very short hospice enrollment... http://goo.gl/cQRnco

Cont.

Related

- *JOURNAL OF THE AMERICAN GERIATRICS SOCIETY* | Online – 30 April 2016 – **'Effect of ownership on hospice service use: 2005-2011.'** In addition to for-profit and not-for-profit hospice agencies differing according to important dimensions, there is substantial heterogeneity within these ownership categories, highlighting the need to consider factors such as agency size and chain affiliation in understanding variations in Medicare beneficiaries' hospice care. http://goo.gl/wwXgBI

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(2):167-172. **'Exploring barriers among primary care providers in referring patients to hospice.'** The results from this survey show that there may be a discrepancy between provider attitudes toward hospice and their actual referral practices. In addition, studies have reported that when providers complete their own living will they are more apt to discuss these documents with patients' and families. http://goo.gl/JJalh6

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 26 April 2016 – **'Economic impact of an advanced illness consultation program within a Medicare Advantage Plan population.'** Members with advanced illness who participated in the Vital Decisions Living Well Consultation Program had significantly lower end-of-life spending compared to matched members who did not participate in the program. The mean cost reduction during the last six months of life for treatment members compared to matched control group members was $13,956 ... during the last six months of life and $9,285 ... during the last three months of life. http://goo.gl/1Mhcug

Providing supportive care to patients with kidney disease

NEPHROLOGY | Online – 26 April 2016 – The field of medicine is recognizing the importance of patient-centered care and quality of life, thoughtfully considering patients' values and goals so care can be effectively tailored to support those goals, which may include the delivery of supportive or palliative care, when necessary. To this end, three "best practices" are provided: 1) Nurture a shared decision-making relationship; 2) Provide meticulous pain and symptom management; and, 3) Provide or collaborate with supportive care or hospice in the treatment of seriously ill kidney disease patients. As renal professionals, it may never be "easy" to face these issues with patients, families, and caregivers; however, applying these best practices will help in providing quality supportive, end-of-life care to patients. http://goo.gl/uAZ8dm

N.B. Listed in the 14 March 2016 issue of Media Watch (#453, p.10) are selected articles on end-of-life care for people living with kidney disease.

Integrating correctional and community health care: An innovative approach for clinical learning in a baccalaureate nursing program

NURSING FORUM | Online – 22 April 2016 – This article demonstrated how medium/maximum prisons can provide an ideal learning experience for not only technical nursing skills but more importantly for reinforcing key learning goals for community-based care, raising population-based awareness, and promoting cultural awareness and sensitivity. In addition, this college of nursing overcame the challenges of initiating and maintaining clinical placement in a prison facility, collaboratively developed strategies to insure student and faculty safety satisfying legal and administrative concerns for both the college of nursing and the prison, and developed educational post-clinical assignments that solidified clinical course and nursing program objectives. Lastly, this college of nursing quickly learned that not only did nursing students agree to clinical placement in an all-male medium- to maximum-security prison despite its accompanying restrictive regulations especially as it relates to their access to personal technology devices, but there was an unknown desire for a unique clinical experience. http://goo.gl/TdfgUI

Media Watch: Back Issues

Back issues of Media Watch are available on the International Palliative Care Resource Center website at: http://goo.gl/frPgZ5

Differences in out-of-pocket costs of healthcare in the last year of life of older people in 13 European countries

PALLIATIVE MEDICINE | Online – 29 April 2016 – Research on the costs of healthcare provision has so far focused on insurer costs rather than out-of-pocket costs. In this study, the proportion of people with out-of-pocket costs ranged from 21% to 96% in different European Union countries. Out-of-pocket costs ranged from 2% to 25% of median household income. Secondary and institutional care was most often the largest contributor to out-of-pocket costs, with care received in a care home being the most expensive type of care in 11 of 13 countries. Multilevel analyses showed that limitations in more than two activities of daily living ... and a total hospitalization time of 3-6 months ... or more than 6 months ... were associated with higher out-of-pocket costs. In total, 24% of the variance on a country level remained unexplained. Variation in out-of-pocket costs for healthcare in the last year of life between European countries indicates that countries face different challenges in making healthcare in the last year of life affordable for all. http://goo.gl/Fnh2uQ

Advance care planning: Not a panacea

PALLIATIVE MEDICINE, 2016;30(5):421-422. The authors distinguish a number of steps in moving advance care planning (ACP) forward. First, there is a need for a broader base of evidence from methodologically sound studies such as randomized controlled trials (RCTs), demonstrating the extent of effectiveness of different models of ACP. Whereas previous studies have shown beneficial effects, ACP is a complex intervention and we lack insight into which elements exactly bring these beneficial effects about and what their potential drawbacks are. Potentially effective elements of ACP are patients' raised awareness that they have options to choose from; having a targeted and structured conversation about preferences for future or current care; the documentation of such preferences; the mere fact that patients, relatives, and care professionals communicate, or the patients' knowledge that their relatives know their preferences and will act on their behalf. The authors recommend further research to disentangle these potentially effective elements of ACP, but also their potentially negative impact, and to explore whether ACP models can be tailored to preferences of patients from different cultures or backgrounds, such as those with low literacy levels. There is also a need to understand who is best equipped to initiate and guide the process of ACP and how that should be done, what the right moment to start ACP is, what can be appropriate settings for ACP, and how the ACP process should be supported over time when a patient's condition deteriorates. Finally, guidance for professionals is needed on how to implement evidence-based ACP models in their practice. Raising healthcare professionals' awareness and educating them about the importance of timely communication with patients and their relatives about what really matters to them should be part of healthcare professional training programs at any level. http://goo.gl/Iq1LtU

Economic (gross cost) analysis of systematically implementing a programme of advance care planning in three Irish nursing homes

BMC RESEARCH NOTES | Online – 26 April 2016 – This before-after trial suggests that there was a significant reduction in hospitalisation rates following the systematic implementation of the Let Me Decide-advance care plan (LMD-ACP) and palliative care education programme in three long-term care (LTC) facilities in southern Ireland. It shows that there were significant cost savings associated with this reduction in admissions. Despite an increase in average length of stay, likely reflecting more complex care needs of admitted residents, costs were estimated to be reduced and scenario analysis projected large significant annual cost savings associated with this reduction in admissions. The economic cost analysis indicates that should the reduced hospitalisations amongst LTC residents as a result of the LMD-ACP process be transferrable to the general LTC population in Ireland then it has the potential to substantially reduce inpatient and ambulance transfer costs. http://goo.gl/LaKgoE

N.B. This issue of *Palliative Medicine* includes several articles on advance care planning (noted in past issues of Media Watch). Journal contents page: http://goo.gl/RxVkVx

Cont.

Related

- *JAMA ONCOLOGY* | Online – 28 April 2018 – **'Family perspectives on aggressive cancer care near the end of life.'** Among family members of older patients [i.e., study participants] with fee-for service Medicare who died of lung or colorectal cancer, earlier hospice enrollment, avoidance of ICU admissions within 30 days of death, and death occurring outside the hospital were associated with perceptions of better end-of-life care. These findings are supportive of advance care planning consistent with the preferences of patients. http://goo.gl/5d5blY

- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2016;18(2):124-130. **'Communication with residents and families in nursing homes at the end of life.'** More than 90% of staff [i.e., study participants] reported that the physician or social worker should communicate about death and dying with residents/families, but only 53% thought that direct care staff should talk with them. Weighted scores for "when communication should occur about death and dying and obtaining a DNR order" revealed significantly ... lower scores for unlicensed staff than registered nurses and licensed practical nurses (i.e., licensed staff), indicating that licensed staff were more likely to initiate conversations on admission or at the care-planning meeting or when the resident's family requested it. No differences were found between staff on communication about obtaining a hospice referral. http://goo.gl/tcTW2g

Islamic theology and the principles of palliative care

PALLIATIVE & SUPPORTIVE CARE | Online – 25 April 2016 – The holistic nature of palliative care (PC), dictated by the multifaceted suffering experienced by patients, calls for giving due consideration to the cultural and spiritual background of the target population. Similarly, the paramount impact of Islamic wholeness on Muslims' perceptions, beliefs, and way of living makes it necessary for non-Muslim PC professionals who are caring for Muslim patients to increase their awareness about the parts of Islamic theology pertinent to the principles of PC. This would include a basic knowledge of the Islamic faith and how Muslims view and cope with the calamity of a life-threatening condition along with the suffering associated with it. Equally important are issues related to the management of symptoms using agents that are normally strictly prohibited by Islamic teachings, including opioids, brain stimulants, and cannabinoids. http://goo.gl/7sdsT7

Noted in Media Watch 1 February 2016, #447 (p.13):

- *JOURNAL OF RELIGION & HEALTH* | Online – 22 January 2016 – **'Ethical dilemmas at the end of life: Islamic perspective.'** Islamic law permits the withdrawal of futile treatment, including all kinds of life support, from terminally ill patients leaving death to take its natural course. However, such decision should only take place when the physicians are confident that death is inevitable. All interventions ensuring patient's comfort and dignity should be maintained. http://goo.gl/9QCq9d

N.B. Additional articles on Islam and end-of-life care are noted in this issue of Media Watch.

Approaches to managing uncertainty in people with life-limiting conditions: Role of communication and palliative care

POSTGRADUATE MEDICAL JOURNAL | Online – 29 April 2016 – Patients with any major illness can expect to experience uncertainty about the nature of their illness, its treatment and their prognosis. Prognostic uncertainty is a particular source of patient distress among those living with life-limiting disease. Uncertainty also affects professionals and it has been argued that the level of professional tolerance of uncertainty can affect levels of investigation as well as healthcare resource use. We know that the way in which uncertainty is recognised, managed and communicated can have important impacts on patients' treatment and quality of life. Current approaches to uncertainty in life-limiting illness include the use of care bundles and approaches that focus on communication and education. The experience in communicating in difficult situations that specialist palliative care professionals can provide may also be of benefit for patients with life-limiting illness in the context of uncertainty. While there are a number of promising approaches to uncertainty, as yet few interventions targeted at recognising and addressing uncertainty have been fully evaluated and further research is needed in this area. http://goo.gl/iTcO3H

Cont.

Related

- *PALLIATIVE MEDICINE* | Online – 29 April 2016 – **'How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data.'** Uncertainty influences patient experience in advanced illness through affecting patients' information needs, preferences and future priorities for care. The authors' typology aids understanding of how patients with advanced illness respond to uncertainty. Assessment of three factors – engagement with illness, information needs, patient priorities, and the period of time that patients mainly focused their attention on – may be a useful starting point to guide clinical assessment and shared decision making. http://goo.gl/lrrXwM

Noted in Media Watch, 18 April 2016, #458 (p.9):

- *INTENSIVE CARE MEDICINE* | Online – 7 April 2016 – **'Addressing uncertainty: What is the role of consensus in end-of-life care.'** Uncertainty is a familiar companion in the practice of medicine, and this lack of certainty is abundant in end-of-life care. Medical decision-making at the end of life occurs in a complex milieu of personal values and beliefs, where tensions between patient autonomy, sanctity of life, quality of life, and social justice abound. http://goo.gl/Qt7O2I

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.

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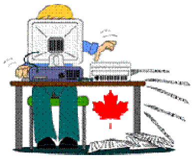
Something Missed or Overlooked?

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



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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *BMC MEDICAL ETHICS* | Online – 27 April 2016 – **'Attitudes towards assisted dying are influenced by question wording and order: A survey experiment.'** The present study demonstrates significant question framing and order effects in a survey on attitudes towards assisted dying. Journalists, politicians and others should be aware of such effects and interpret survey results accordingly, as should researchers who conduct attitude surveys in bioethics. http://goo.gl/ya0uwx

- *DEATH STUDIES* | Online – 19 April 2016 – **'Assisted suicide for prisoners? Stakeholder and prisoner perspectives.'** The authors interviewed thirty-five older prisoners and twenty-four stakeholders (prison staff, prison healthcare professionals and policy makers) about healthcare for prisoners. In all, six prisoners and three stakeholders spontaneously expressed their attitudes concerning assisted suicide. Some prisoners seek assisted suicide for medical reasons and others because they regard spending the rest of their lives in prison as undignified. However, stakeholders identified several ethical and practical challenges in providing assisted suicide to prisoners. http://goo.gl/M1Fsz1

- *NEDERLANDS TIJDSCHRIFT VOOR GENEESKUNDE* | Online – 20 April 2016 – '**Assessing unbearable suffering in relation to euthanasia.**' Dutch law permits physicians to perform euthanasia, provided they fulfil six criteria of due care. Prominent among these is the requirement that they are convinced that the patient is suffering unbearably. But how can they be sure of that? The problem seems to be that this criterion is too subjective on two scores: it makes the patient dependent on the empathic capacities of his physician, and it would be arrogant for the physician to deny that the patient is suffering unbearably if that is what the patient tells them. https://goo.gl/Qe8IKG

  N.B. Dutch language article

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/0Q1Mh4

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): http://goo.gl/XrhYCH

Canada

ONTARIO | HPC Consultation Services (Waterloo Region Wellington County): http://goo.gl/AhlqvD

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

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