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.

20 June 2016 Edition | Issue #467



Compilation of Media Watch 2008-2016 ©

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Facilitating effective, empathetic communication in end-of-life care: Scroll down to <u>Specialist</u> <u>Publications</u> and 'Promoting quality care in patients with cancer with limited English proficiency: Perspectives of medical interpreters' (p.15), in *Psycho-Oncology.*

Canada

Can doctors actually predict how long patients have left?

THE GLOBE & MAIL | Online – 17 June 2016 – Many physicians will shy away from making specific predictions. But patients and their families often want some idea about how long they might have left. And that desire to have a window on the future is certainly understandable. However, the difficulty of making an accurate prediction was revealed in a study led by Dr. Debbie Selby, a palliative care (PC) physician at Sunnybrook Health Sciences Centre in Toronto.¹ The researchers reviewed data collected on 1,622 patients diagnosed with incurable diseases. PC doctors assessed each of the patients. During the assessments, the doctors recorded details about the patients and gave an estimate of survival time. In particular, the doctors said if they thought a patient would live less than a day, one to seven days, one to four weeks, one to three months, three to six months, six to 12 months or more than a year. The estimates were not given to the patients, so the doctors weren't hampered by how their predictions might be received. The doctors were right only half the time in cases involving patients who had less than a month to live and also for those who survived longer than a year... Predictions of between one month and one year were even less accurate. The doctors were correct only one-third of the time. http://goo.gl/6b775F

 'Clinician accuracy when estimating survival duration: The role of the patient's performance status and time-based prognostic categories,' *Journal of Pain & Symptom Management*, 2011;42(4):578-588. <u>http://goo.gl/W2cr2g</u>

Noted in Media Watch, 18 January 2016, #445 (p.5):

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 14 January 2016 – 'Accuracy of physician prognosis in heart failure and lung cancer: Comparison between physician estimates and model predicted survival.' Cardiologists [i.e., study participants] were more accurate in predicting survival in heart failure symptoms and reduced ejection fraction compared to generalists and oncologists, but no different at predicting heart failure symptoms and preserved ejection fraction. Physicians felt more uncomfortable discussing palliative care with heart failure patients compared to lung cancer. http://goo.gl/Fp686D

N.B. Selected articles on the accuracy of prognosis are noted in the issue of the Media Watch of 16 February 2015, #397 (pp.4-5).

Mourning families increasingly blocking organ donations of loved ones

ONTARIO | *The Toronto Star* – 16 June 2016 – Grieving families are blocking the organ donations of one in five Ontarians who registered to donate before they died, the *Star* has learned. Data obtained by the *Star* from the Trillium Gift of Life Network reveals how often opportunities for potentially life-saving transplants are lost because of family objections – a number that has steadily risen over the past three years. In 2013, the province's organ and transplant registrar recorded 14.5% of families (representing 26 registered donors) who refused consent, a number that climbed to 21.1% (62 donors) last year. Given that one donor can save eight lives, the would-be donors could have meant a lot of good news for 1,524 people in need of an organ transplant on Ontario's wait list. Experts say the refusals could prove fatal to those left waiting for a donor. Under the current system, anyone 16 or older can register online, by mail or in person at Service Ontario kiosks to consent to donate their organs – hearts, lungs and livers – and/or tissues, such as skin, bones, heart valves and eyes. But whether a donor's wishes are honoured is another question. The province's Trillium Gift of Life Act does not specifically require family to reaffirm a registered donor's consent. However, because the act calls for donations to be cancelled if there is "reason to believe that (consent) was subsequently withdrawn," Trillium's practice is to ask relatives if their loved one might have changed his or her mind. https://goo.gl/RSFKf6

Noted in Media Watch, 1 December 2014, #386 (p.11):

 PEDIATRIC TRANSPLANTATION | Online – 25 November 2014 – 'Palliative and end-of-life care in pediatric solid organ transplantation.' Transplant teams do not always make timely referrals to palliative care due to various clinician and perceived family barriers, an important one being the simultaneous, active care plan each patient would have alongside an end-of-life plan. <u>http://goo.gl/jkTXt8</u>

Noted in Media Watch, 9 July 2012, #261 (p.9):

 END OF LIFE JOURNAL, 2012;2(2). 'The barriers to organ and tissue donation in palliative care.' This article explores the involvement of palliative care patients in decisions about donating their tissues, why families may be reluctant to consent to donating organs/tissues of deceased loved ones, and reasons why nurses are wary of discussing the possibility of donation with patients and/or their next of kin. <u>http://goo.gl/dOua0l</u>

Rates of chronic disease higher among aboriginals, Cancer Care Ontario says

ONTARIO | The Canadian Press – 15 June 2016 – Cancer Care Ontario is calling on the province to take urgent action to help a number of chronic health problems among aboriginal communities.¹ The organization says rates of disease are higher among first nations, Inuit and Metis populations than their non-aboriginal counterparts. They say 63% of First Nations people living off reserve and 61% of Metis suffer from one or more chronic conditions, compared to 47% of the general population. Cancer Care Ontario is recommending policies the Ontario government could put in place to combat diabetes, heart disease, cancer and respiratory disease. http://goo.gl/SWeGcu

Extract from Cancer Care Ontario report

There is a perception that palliative care is limited to the last days and weeks of life. A palliative approach to care is appropriate from the time of diagnosis until the end of life, aiming to prevent and ease suffering to improve quality of life throughout the illness. Palliative and end-of-life care initiatives focus on holistic patientcentred care to manage symptoms and pain, reduce caregiver burden, and avoid unnecessary treatments and hospitalizations. There are also opportunities to improve emotional support, culturally sensitive communication, and transitions between specialty cancer care and primary care.

1. 'Aboriginal Cancer Strategy 2015-2109,' Cancer Care Ontario, June 2016. https://goo.gl/UCv8NK

Selected articles on end-of-life care for First Nations peoples

- ONTARIO | CBC News 24 September 2015 'Palliative care poor in First Nations communities, researcher says.' Choosing to live out their last days at home is not an option for many First Nations people. Mary Lou Kelley, a professor at Lakehead University, says federal health care dollars that would help First Nations people receive end-of-life care at home have not kept up with the increasing demand. [Noted in Media Watch, 28 September 2015, #429 (p.1)] http://goo.gl/2DJKB5
- PALLIATIVE & SUPPORTIVE CARE | Online 15 June 2015 'Indigenous people's experiences at the end of life.' The findings of this study provide a beginning to an understanding of the end-of-life experiences of indigenous peoples. More research is critical if palliative care services, the healthcare system, and healthcare providers are to reduce barriers to "preparing the spirit" for the journey at the end of life. [Noted in Media Watch, 22 June 2015, #415 (p.14)] <u>http://goo.gl/i2DeQU</u>
- CTV NEWS | Online 28 April 2015 'Auditor General takes aim at First Nations health...' The quality of health care in remote First Nations communities is sorely lacking¹ ... a conclusion that aboriginal leaders call a further indictment of how they are being treated by Ottawa. [Noted in Media Watch, 4 May 2015, #408 (p.2)] http://goo.gl/QinsS5
 - 'Access to Health Services for Remote First Nations Communities,' Auditor General of Canada, Spring 2015. <u>http://goo.gl/UTAMBv</u>

N.B. There is no mention in the Auditor General's report of end-of-life care.

"Things have changed," University de Sherbrooke medical school reflects on end-of-life care

QUEBEC | The Record (Sherbrooke) – 14 June 2016 - When it comes to end-of-life care, the rules in Quebec have changed. With Quebec's Act Respecting End of Life Care having come into effect last December the medical world has to face a new reality and adjust its practices. As of Tuesday morning, the University of Sherbrooke's Faculty of Medicine & Health Sciences was ready to share its new approach. "Things have changed" said Pierre Cossette, Dean of the faculty. "We have a duty to reflect, to offer training activities to our professors, and to review certain practices with our students to enable them to become more knowledgeable about end-of-life situations and respond appropriately to the wishes of patients and their loved ones in

this new context." Calling the change a paradigm shift; a transition so big that it has an impact on the way everything else is done, Cossette said that the faculty assembled a working group to tackle the changes brought about by the new legislation in order to be able to digest the information and adapt to the new reality as quickly as possible. <u>http://goo.gl/xp3b9v</u>

Specialist Publications

'Palliative care delivery across health sectors: A population-level observational study' (p.15), in *Palliative Medicine*.



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

Why Canada needs publicly funded insurance for home care

THE GLOBE & MAIL | Online - 11 June 2016 -The chronic diseases of today's aging population render the existing definition of medicare coverage obsolete. Our health system routinely fails to address the complex needs of seniors. Let's face it: Canadian baby boomers are getting older and many will soon require home care and longterm care. We need important reforms now to fund the health care system that they will need in the all too near future. The perverse effects of our current system of health funding result in the use of costly resources from hospitals and other institutions to respond to disabilities and chronic conditions instead of using more cost-effective home care services. In the current funding paradigm, which prioritizes hospital and acute care, it is unrealistic to expect that home care will be

Noted in Media Watch, 8 April 2013, #300 (p.2):

prioritized. It is equally unrealistic to believe the elderly will have the fundamental freedom to choose their living environment or care providers without basic reforms in how the health system is financed. <u>http://goo.gl/PF8hC7</u>

Extract from The Globe & Mail article

As it stands now, many older Canadians in most provinces have to endure the tyranny of public institutions which decide the level of home care services provided, the limits of any home care provided, and even the time a senior should leave their home for longterm care and where they should move to. This is unacceptable.

- CTV NEWS | Online 4 April 2013 'Provinces need to follow through on home care funding commitments: Report.' Canada's provinces and territories talk a good game when it comes to funding in-home health care, but a new report is urging all orders of government to put their money where their mouths are.¹ <u>http://goo.gl/DZ97PF</u>
 - 1. 'Portraits of Home Care,' Canadian Home Care Association, April 2013. http://goo.gl/INlipb

Assisted (or facilitated) death

Representative sample of recent news media coverage:

THE GLOBE & MAIL | Online - 17 June 2016 - 'Senate backs down, passes assisted-dying legislation.' Canada has its first doctor-assisted dying law, which excludes those who are suffering intolerably but not at the end of life, after senators backed down from their fight against the House of Commons and passed the Liberal government's historic bill. The law, which received royal assent ... sets out national guidelines with strict safeguards for medical assistance in dying. The law clarifies who is eligible for assisted death and outlines the process, such as requiring two independent witnesses and medical opinions. Most notably, it excludes those whose natural deaths are not "reasonably foreseeable" - a major point of contention between elected MPs and senators, who wanted the bill to include patients who are not terminally ill. The House of Commons agreed ... to accept most of the Senate's seven amendments to Bill C-14, such as providing a consultation on palliative care options and banning beneficiaries from signing consent forms on behalf a patient, but not the major proposal to remove the end-oflife requirement. The Senate had rejected a proposal to include advance consent for those suffering from dementia and other degenerative diseases in the bill. But both houses adopted an amendment to study that issue and others within two years. http://goo.gl/jNlwB6

Specialist Publications

'Physician-assisted death and conscientious objection: Implications for critical care nurses' (p.17), in *Canadian Journal of Critical Care Nursing.*

""Who owns my life?": Women, legislation, and the right to death' (p.17), in Sojourners Undergraduate Journal of Sociology.

- THE NATIONAL POST | Online 16 June 2016 'Can inmates ask to die? Canada still needs to decide how assisted death bill will impact prison population.' By law, inmates must have the same standard of health care they would on the outside. But Canada's prison watchdog has raised concerns about how inmates are cared for in their final years. About a quarter of the prison population is over the age of 50 and inmates tend to have more health problems and shorter life spans compared to the general public. Bill C-14 would amend the legislation that covers prisons ... so an investigation is not required if a prisoner dies with medical assistance. http://goo.gl/uAKo4Y
- CBC NEWS | Online 14 June 2016 'At least 31 Canadians have asked for a doctor-assisted death since January.' At least 31 Canadians have reached out to their doctor asking for help to die since mid-January. But the number may actually be significantly higher, as at least one province admits it isn't tracking medically assisted death requests, while another isn't ready to release data on the issue. <u>http://goo.gl/eq7jnr</u>

<u>U.S.A.</u>

Dying in a hospital means more procedures, tests and costs

NATIONAL PUBLIC RADIO | Online - 15 June 2016 – People who die in the hospital undergo more intense tests and procedures than those who die anywhere else. An analysis by Arcadia Healthcare Solutions also shows that spending on people who die in a hospital is about seven times that on people who die at home. The work confirms with hard data what most doctors and policymakers already know: Hospital deaths are more expensive and intrusive than deaths at home, in hospice care, or even in nursing homes. Arcadia analyzed all the Medicaid claims data for a private Medicaid insurance company in one Western state and detailed how many billable medical procedures each patient received and where. Patients in hospitals were billed for far more medical interventions in the last days of their lives than people who died in other settings. The company declined to name the state or company. The study showed that 42% of patients died at home at a cost of about \$4,760 for their last month of life, while 40% died in a hospital at a cost of \$32,379. Dying in a nursing home was the second most expensive locale, inpatient hospice was third and an emergency room was fourth. The picture is more complicated than the data show, says Dr. Lachlan Forrow, a professor of medicine and medical ethics at Harvard University. Many patients move from home to hospice to hospitals and back during the last 30 days of life. And some may end up in the hospital because their pain or symptoms weren't adequately controlled at home. Still, he says, hospitals are just not good at caring for dving people. http://goo.gl/bVRBBf

Where people died and how much the final month of care cost: NPR report

- 42% of patients died at home: \$4,760
- 40% of patients died in the hospital: \$32,379
- 7% of patients died in hospice: \$17,845
- 7% of patients died in a nursing facility: \$21,221
- 5% of patients died in the ER: \$7,969

Source: Arcadia Healthcare Solutions

Specialist Publications

'First Medicare demonstration of concurrent provision of curative and hospice services for end-oflife care' (p.9), in *American Journal of Public Health*.

'Identification of four unique spending patterns among older adults in the last year of life challenges standard assumptions' (p.9), in *Health Affairs*

'Survey on clinician perceptions and practices regarding goals of care conversations' (p.13), in *Journal of Palliative Care*

'The impact of reported hospice preferred practices on hospital utilization at the end of life' (p.9), in *Medical Care*.

'End-of-life care intensity and hospice use: A regional-level analysis' (p.9), in *Medical Care*. Noted in Media Watch, 22 September 2014, #376 (p.4):

 NATIONAL PUBLIC RADIO | Online – 21 September 2014 – 'Terminally ill, but constantly hospitalized.' It turns out that in the New York metropolitan region patients opt for aggressive treatment much more often than other Americans. The reasons they do this are many, but most experts agree that it has less to do with the unique characteristics and desires of people in New York and New Jersey than the health care system and culture that has evolved here. <u>http://goo.gl/Tf0WII</u>

Noted in Media Watch, 11 June 2013, #310 (p.4):

 THE DARTMOUTH INSTITUTE | Online – 12 June 2013 – Tracking Improvement in the Care of Chronically III Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life. Often the care that patients receive, both at the end of life and when less ill, is not the care that informed patients and families would choose. <u>http://goo.gl/aRxuH6</u>

Patient wishes are tough to see in electronic health records: End-of-life preferences aren't being carried out

MINNESOTA | *The Star Tribune* (Minneapolis) – 11 June 2016 – Electronic health records are now ubiquitous in hospitals, and the systems give patients what could be a better way to communicate their wishes on treatment options at the end of life. But in too many cases, physicians using the systems struggle to find the documents. About 96% of U.S. hospitals last year were using an electronic health record system, with total spending on the systems in the neighborhood of \$3 trillion, estimated Ross Koppel, a researcher at the University of Pennsylvania. Record systems can store advance directives, where patients can explain preferences on end-of-life care options such as avoiding resuscitation, feeding tubes or ventilators. The documents can help physicians understand a patient's wishes when the patient can't talk. But less than one-third of ER doctors feel very confident they could locate information in the electronic record, according to a survey published by medical researchers in May. <u>http://goo.gl/JfK9CR</u>

Noted in Media Watch, 21 March 2016, #454 (p.5):

 USA TODAY | Online – 19 March 2016 – 'Electronic records and end-of-life plans.' In a perfect world, patients with advance directives would be confident that their doctors and nurses – no matter where they receive care – could know in a split second their end-of-life wishes. But this ideal is still in the distance. Patients' documents often go missing in maze-like files or are rendered unreadable by incompatible software. <u>http://goo.gl/yIN5IQ</u>

Transition from hospital to home can be dangerous for patients

MISSOURI | *St. Joseph News-Press* – 11 June 2016 – The growing field of home health care can extend the continuum of care into the home, but new studies have shown that the transition from hospital to home remains a dangerous time for patients. A study of 400 patients found that almost 20% experienced adverse side effects within three weeks of hospital discharge, nearly 75% of which could have been prevented or lessened.¹ Adverse drug events were the most common complication, as well as hospital-acquired infections and procedural complications. According to the study ... nearly 40% of the patients were discharged with test results pending. http://goo.gl/zJjLQf

1. 'The incidence and severity of adverse events affecting patients after discharge from the hospital,' *Annals of Internal Medicine*, 2003;138(3):161-167. <u>http://goo.gl/h1jPBm</u>

Cont. next page

Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.18.

Noted in Media Watch, 24 February 2014, #346 (p.9):

JOURNAL OF GENERAL INTERNAL MEDICINE | Online – 21 February 2014 – 'Regardless of age: Incorporating principles from geriatric medicine to improve care transitions for patients with complex needs.' This article provides a framework for incorporating geriatrics principles into care transition activities by... 1) Identifying factors that make transitions more complex; 2) Engaging care "receivers" and tailoring home care to meet patient needs; 3) Building "recovery plans" into transitional care; 4) Predicting and avoiding preventable readmissions; and, 5) Adopting a palliative approach, when appropriate, that optimizes patient and family goals of care. <u>http://goo.gl/cU1hn9</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE ECONOMIST | Online 15 June 2015 'The number of mentally ill seeking help to die is rising. Are the rules being twisted?' Since 2002, when The Netherlands legalised assisted dying, its laws have been held up elsewhere as a model. But recent figures from the Dutch Euthanasia Review Committee have given some campaigners pause. It is not the total number of deaths under the law's provisions that bother them though it has increased by 76% since 2010... Rather, it is 56 individual cases: those who sought, and received, doctor-assisted deaths because of psychiatric disorders. http://goo.gl/VodpVU
- THE ECONOMIST | Online 13 June 2016 'How assisted suicide is gradually becoming lawful in America.' [In implementing the End of Life Option Act], California largely cribbed from similar legislation in Oregon, Vermont and Washington. With the End of Life Options Act, the number of Americans potentially eligible to secure an early death rises to about 50 million, or roughly one-sixth of the total population. But the option will likely remain the choice of few people facing the end of their lives. The law in Oregon, which pioneered doctor-assisted dying, has not spurred a rash of suicides: over nearly two decades with the Death With Dignity Act, only 991 patients have used the programme to end their lives. Another 600 or so who obtained the medication did not end up taking it. http://goo.gl/pXh5HI

International

Doctors blame many factors for futile care, themselves included

AUSTRALIA | Reuters – 17 June 2016 – Doctors who were asked about causes of inappropriate care at the end of life didn't have to look far to place blame. They blamed themselves. Australian researchers interviewed 96 physicians from 10 medical specialties and asked them to describe situations when patients received end-oflife care that the doctors felt was inappropriate.¹ Futile medical treatment at the end of life has been shown to harm patients, cause moral distress to clinicians and waste scarce resources... But 96% of physicians pointed to themselves or "doctor-related factors" - as the main drivers of futile treatment. Poor communication, emotional attachment to patients, and aversion to death were also among the causes they cited. Patient-related factors were important, too. Ninety-one percent of the doctors cited reasons such as family or patient requests for treatment, prognostic uncertainty and not knowing the patient's wishes as contributors to inappropriate care. Close to 70% of the surveyed doctors also cited hospital-related causes, such as specializations, medical hierarchy and time pressure, as factors in futile care. <u>http://goo.gl/TpOnZA</u>

Specialist Publications

'End-of-life care in the intensive care unit: Report from the Task Force of World Federation of Societies of Intensive & Critical Care Medicine' (p.11), in *Journal of Critical Care*.

1. 'Reasons doctors provide futile treatment at the end of life: A qualitative study,' *Journal of Medical Ethics*, 17 May 2016. [Noted in Media Watch, 23 May 2016, #463 (p.13)] <u>http://goo.gl/K3y4Fn</u>

House of death or house of hope: First Belarusian children's hospice

BELARUS | *Belarus Digest* (Minsk) – 14 June 2016 – Belarusian Children's Hospice (BCH) was tolerated rather than welcomed when it first came on the scene in 1994. Many people were suspicious of it as a western idea that had no place in Belarusian healthcare, others did not understand its aims, some regarded it as a "house of death" instead of a house of light, joy and good quality of life. Gradually both the Belarusian public, media, medical services, ministries and other governmental departments have come to gain a better understanding of the huge bene-



fits a children's hospice. Namely what added value it brings to the country's healthcare, both in terms of vastly improved quality of care and quality of life of the chronically and terminally ill child and their family. From the financial standpoint it also means huge savings for the state medical service when a child on 24-hour care is at home instead of in a hospital intensive care department. For the past decade BCH has trained medics from all over Belarus in children's palliative care and hopefully will be able to expand these programmes in its new education centre. http://goo.gl/fTKO2X

N.B. Belarusian Children's Hospice – Website > <u>http://goo.gl/wGE17V</u>; Friends of > <u>http://goo.gl/bPTPN3</u>

Noted in Media Watch, 21 September 2015, #428 (p.8):

ARCHIVES OF DISEASE IN CHILDHOOD | Online – 14 September 2015 – 'Children's palliative care in low- and middle-income countries.' This paper reviews the status of children's palliative care (PC) services in low- and middle-income countries – highlighting examples of best practice among service models in Malawi, Indonesia and Belarus... While much has been achieved in PC for adults, less attention has been devoted to the education, clinical practice, funding and research needed to ensure children and young people receive the PC they need. http://goo.gl/gy6DpL

Potentially abusive behavior may be common among family caregivers

IRELAND | Reuters – 14 June 2016 – When elderly people are dependent on family caregivers, potentially abusive carer behaviors are common and need to be detected early, before the situation deteriorates into elder abuse, researchers warn.¹ In a survey of family caregivers, more than a third had engaged in potentially harmful behavior toward their older family member in the previous three months Such harmful behaviors might include insulting, swearing, or screaming or yelling at the older person or roughly handling them. Often, caregivers may not realize their behaviors are potentially harmful to their care recipient. Out of the 4,000 caregivers contacted, 2,311 completed the survey. The caregivers ranged in age from 19 to 92. Most were women. About 50% had been caring for a parent and 31.1% had been caring for a spouse for an average of 6.8 years. More than half had only some or no formal education, and most were unemployed. http://goo.gl/sZFByf

1. 'The prevalence of potentially abusive behaviours in family caregiving: findings from a national survey of family carers of older people,' *Age & Ageing*, 25 May 2016. <u>http://goo.gl/CEAwCz</u>

Noted in Media Watch, 27 December 2010, #181 (p.7):

 JOURNAL OF AMERICAN SCIENCE, 2011;7(1):206-214. 'Correlation between caregivers' burnout and elderly psychological abuse.' Media coverage of abuse in elders homes has made the public knowledgeable about-and outraged against-abusive treatment in those settings, providing education, appropriate training and counselling for the caregivers to find solutions for their problems and the problems of the elderly and about the risk factors for abuse. <u>http://goo.gl/Aa3kjc</u>

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

Assisted (or facilitated) death

Representative sample of recent news media coverage:

• FRANCE | Radio France Internationale – 16 June 2016 – 'French doctors asked to decide in right-to-die case.' A French court ordered doctors to decide whether a patient in a vegetative state should be allowed to die after years of legal battles that have torn his family apart. Vincent Lambert, 39, was left severely brain damaged and quadriplegic as a result of a 2008 road accident, but has been kept alive through artificial nutrition and hydration. Lambert has become the centre of a labyrinthine judicial battle that has gone all the way to the European rights court and ignited a heated debate over euthanasia in France. In the latest court ruling, the doctors caring for Lambert were ordered to resume consultations with medical experts and come to a decision over his fate. http://goo.gl/H80IAb

Specialist Publications

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

First Medicare demonstration of concurrent provision of curative and hospice services for end-of-life care

AMERICAN JOURNAL OF PUBLIC HEALTH | Online – 16 June 2016 – Hospice developed in the U.S. in the 1970s as a way to address unmet needs for end-of-life care (EOLC): support for pain and symptom management provided in the location and manner the patient and family prefer. In Europe and Australia hospice is available from time of diagnosis of an advanced life-limiting illness onward, but in the U.S. the Medicare hospice benefit restricts eligibility for these services to patients who no longer receive curative treatment. The authors provide background and analysis of the first Medicare hospice demonstration in 35 years that will test the concurrent provision of curative and hospice services for terminally ill individuals with a life expectancy of six months or less. This demonstration is a harbinger of potential policy changes to hospice and palliative care in the U.S. that could reduce barriers to EOLC that aligns with patient and family preferences as demand for care increases with an aging population. http://goo.gl/hEuGQG

Related

- HEALTH AFFAIRS | Online 15 June 2016 'Identification of four unique spending patterns among older adults in the last year of life challenges standard assumptions.' The assumption that health care spending skyrockets at the end of life might suggest that policy makers should target the last few months of life to control costs. However, spending patterns leading up to death have not been fully examined. The authors applied a new methodology to administrative claims data for older Medicare beneficiaries who died in 2012 to characterize trajectories of health care spending in the last year of life. They identified four unique spending trajectories among decedents... http://goo.gl/TEZrGr
- MEDICAL CARE, 2016;54(7):657-663. 'The impact of reported hospice preferred practices on hospital utilization at the end of life.' Patients who were asked where they wanted to die upon entering hospice had lower rates of hospitalization at the end of life, as did those in hospices that monitored symptoms more frequently, according to a new study... For-profit hospices have persistently high rates of hospitalization... Findings determined that while the hospitalization of patients after being enrolled in hospice varied considerably, two of the six preferred practices examined (namely assessing patient preferences for site of death and monitoring symptoms at least every dew days) were associated with significantly lower hospitalization rates of patients following hospice enrollment. http://goo.gl/prUukM
- MEDICAL CARE, 2016;54(7):672-678. 'End-of-life care intensity and hospice use: A regional-level analysis.' End-of-life care (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 vs. the lowest quintiles of intensity in EOLC, regions with more intensive care had higher rates of very short hospice enrollment. <u>http://goo.gl/VEdrxY</u>

Navigating the transition of critical care to end-of-life care using a strengths-based nursing approach

CANADIAN JOURNAL OF CRITICAL CARE NURSING, 2016;27(2):17. Nurses working in critical care environments are often challenged with the difficulty of transitioning patients and families from aggressive and curative treatments to a palliative, end-of-life focus. Current research addressing the role of nurses during this pivotal transition is sparse and reveals the need to explore the ways in which nurses can facilitate this emotional experience for families. Nurses play a pivotal role in patient care, as they spend more time with patients and their families at the end of life than any other health care professional. As a result, critical care nurses are often confronted with the challenges of supporting patients and families through painful transitions, complicated ethical dilemmas, and the agonizing decision-making process surrounding this shift to a palliative approach to care. In an intensive care unit (ICU) setting there may be the perception that little can be done for patients receiving palliative care (PC). However, palliative patients often have complex medical needs and are typically suffering from multiple disease processes. The goals of PC are meant to support the multidimensional needs of patients and family members before, during, and after death. Using a strengths-based approach to care, which is collaborative and multidisciplinary and embodies values of holism, patient-centredness and the creation of a healing environment can be useful in the support of families experiencing the difficulty of accompanying a loved one at the end of life. http://goo.gl/HUo2Xr

End-of-life care in Germany

An analysis of contributions to the main German chat forum for cancer patients regarding palliative care

DEUTSCHE **MEDIZINISCHE** WOCHEN-SCHRIFT, 2016;141(12):e106-e114. Goal of this study is the analysis of the most important online forum for cancer patients, Cancer Compass, concerning palliative care (PC). The general practitioner is the main source of information, but the Internet is gaining importance. The forum users often offer good explanations of cancer and PC and also refer to web pages with exact definitions. Reliability of web pages is a one issue discussed in the forum. Patients are afraid of pain and dying. Relatives fear for the patient, are overwhelmed and experience existential problems. Both groups use the Cancer Compass to share experiences and get psychological support. Thus Cancer Compass offers a possibility to discuss options for improving quality of life. Especially in the initial phase of care, many users are uncertain what PC means. The treatment of pain represents the main concern of patients and their families. Whereas dedicated PC wards are rated positively, users speak less positively

N.B. German language article.

about pain treatment in general wards in home care. In general, inpatient PC was rated positively. However information regarding outpatient care is lacking. Family care is mostly not possible on account of geographical distance. One point of criticism is the discrepancy between urban and rural areas. Patients place more trust in their general practitioner than in hospital doctors. https://goo.gl/7G2sqt

Extract from Deutsche Medizinische Wochenschrift article

Cancer Compass is an important medium for patients and their families to share information on PC. In order to improve the reliability of information from the Internet, a certification of websites would be helpful. In web forums, moderators may improve the quality of information.

Media Watch: Back Issues

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

Attitudes towards end-of-life decisions and long-term care dependency: Results of a representative survey of Austrians aged 50+

DAS GESUNDHEITSWESEN | Online – 14 June 2016 – Existing research on attitudes in the general population regarding end-of-life decisions has included neither old age long-term care dependency nor worries regarding age(ing). Twenty-nine percent of the [survey] respondents indicated not wanting to live on as a severely care-dependent older person. In the case of an older care-dependent person, 48.5% approved of forgoing life-sustaining treatment, 41.7% of assisted suicide and 34.1% of euthanasia if requested. Worries about old age and ageing were widespread and highly worried respondents were more inclined to support assisted suicide and euthanasia compared to those less worried. Worries and negative stereotypes regarding age(ing) and long-term care dependency should be addressed by information campaigns. https://goo.gl/jTz0li

N.B. German language article.

Interprofessional collaboration between family doctors and nurses at the end of life. Challenges of community-based palliative care in Switzerland

JOURNAL OF COMMUNITY & PUBLIC HEALTH NURSING | Online – 31 May 2016 – Results of this study show that interprofessional collaboration in community-based palliative care (PC) is highly challenging due to different factors: First of all deficits related to organizational aspects of work constitute a source for conflict: the asynchrony of working hours of family doctors and nurses prevent personal contact, communication and trust building. More than that different professional values regarding PC and dying can cause disturbances in collaboration and affect the personal relationship between professionals negatively. Uncertainties regarding leadership and a failure of meta-communication provide further impediments for inter-professional collaboration. The article provides recommendations how to support and instruct collaborative processes between family doctors and nurses in end-of-life care. http://goo.gl/kUfEkf

End-of-life care in the intensive care unit: Report from the Task Force of World Federation of Societies of Intensive & Critical Care Medicine

JOURNAL OF CRITICAL CARE, 2016;34:125-130. The objective [of the Task Force] was to develop a generic statement about current knowledge and to identify challenges relevant to the global community that may inform regional and local initiatives. An updated summary of published statements on end-of-life care (EOLC) in the ICU from national Societies is presented, highlighting commonalities and differences within and between international regions. The complexity of EOLC in the ICU, particularly relating to withholding and withdrawing life-sustaining treatment while ensuring the alleviation of suffering, within different ethical and cultural environments is recognized. Although no single statement can therefore be regarded as a criterion standard applicable to all countries and societies, the World Federation of Societies of Intensive and Critical Care Medicine endorses and encourages the role of member societies to lead the debate regarding EOLC in the ICU within each country and to take a leading role in developing national guidelines and recommendations within each country. <u>http://goo.gl/FoABJP</u>

Extracts from Journal of Critical Care article

The success of intensive care is not to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death. GR Dunstan, University of London, 1984

Related

INTENSIVE & CRITICAL CARE NURSING | Online – 7 June 2016 – 'Perceptions of a good death: A qualitative study in intensive care units in England and Israel.' Four themes were identified that were similar in both countries: 1) Timing of communication; 2) Accommodating individual behaviours; 3) Appropriate care environment; and, 4) Achieving closure, which they perceive prevent, and contribute to, a good death and good quality of end-of-life care. Themes identified by participants may provide a framework for guiding end-of-life discussions in the intensive care unit. http://goo.gl/iPYTTd

Selected articles on end-of-life care in the intensive care unit

- REVISTA BIOÉTICA, 2016;24(1):54-63. 'Life and death in the ICU: Ethics on the razor's edge.' This article seeks to address some ethical issues experienced on the borders of life and death in Intensive Care Units (ICUs). It is in this complex context that difficult ethical issues emerge: there are no objective criteria for admissions to the ICU, ICUs can be overcrowded with patients without diagnosis and there are difficulties in limiting treatment, which results in medical procedures that only prolong the dying process of the patient. [Noted in Media Watch, 11 April 2016, #457 (p.13)] http://goo.gl/HMPohi
- ACTA ANAESTHESIOLOGICA SCANDINAVICA | Online 8 October 2015 'Great variation between ICU physicians in the approach to making end-of-life decisions.' The authors explored different strategies ICU physicians use when making EOL decisions, and whether attitudes towards EOL decisions differ between a small-group simulation setting and a large-group plenary setting. The study took place during a Scandinavian anaesthesiology and intensive care conference. [Noted in Media Watch, 19 October 2015, #432 (p.9)] http://goo.gl/mfkIWK
- AUSTRALIAN CRITICAL CARE | Online 18 September 2015 'End-of-life decisions in the Intensive Care Unit (ICU): Exploring the experiences of ICU nurses and doctors: A critical literature review.' There were differences reported in the decision making process and collaboration between doctors and nurses, with overall accountability assigned to the physician. Role ambiguity, communication issues, indecision on futility of treatment, and the initiation of end-of-life discussions were some of the challenges. [Noted in Media Watch, 28 September 2015, #429 (p.10)] http://goo.gl/gUUy0L

Compromised autonomy: When families pressure patients to change their wishes

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 15 June 2016 – When patients are unduly pressured by their families to make medical decisions that are not in line with previously held values, beliefs, or perspectives, autonomy is compromised. A case example, based on a clinical ethics consultation, is used to highlight the complexities of compromised autonomy secondary to family coercion and manipulation at the end of life. Decision making in the context of family involvement and relational autonomy is explored along with effects of caregiver stressors, patient/family disagreements, and the nuances of substituted judgment. The article closes with a discussion of universal strategies for best working with and advocating for patients who are experiencing compromised autonomy. http://goo.gl/WguFRf

Integrating palliative care in pediatric oncology: Evidence for an evolving paradigm for comprehensive cancer care

JOURNAL OF THE NATIONAL COMPREHENSIVE CANCER NETWORK, 2016;14(6):741-748. The demonstrated benefit of integrating palliative care (PC) into cancer treatment has triggered an increased need for PC services. The trajectory of integrating PC in comprehensive cancer centers, particularly pediatric centers, is unknown. The authors describe their 8-year experience of initiating and establishing PC with the Quality of Life Service (QoLS) at St. Jude Children's Research Hospital (Memphis, Tennessee). Since its inception, the QoLS experienced a dramatic increase in referrals and encounters per patient, increased use by all clinical services, a trend toward earlier consultation and longer term follow-up, increasing outpatient location of death, and near-universal PC involvement at the end of life. The successful integration of PC in a comprehensive cancer center, and the resulting potential for improved care provision over time, can serve as a model for other programs on a broad scale. <u>http://goo.gl/G8kCHJ</u>

Cont.

Related

• NURSING CHILDREN & YOUNG PEOPLE, 2016;28(5):16-21. 'Storyboarding as an aid to learning about death in children's nursing.' Although education for nurses about dealing with death has been studied, there is limited research into the education of those working with dying children and how effective it is in preparing them to deal with the situation. This article examines the use of storyboarding as a creative teaching tool to enable children's nursing students to reflect on their experiences of working with children and families in death situations. http://goo.gl/uAiQky

Survey on clinician perceptions and practices regarding goals of care conversations

JOURNAL OF PALLIATIVE CARE | Online – 15 June 2016 – Early conversations between clinicians and patients about goals of care may improve patients' quality of life and prevent non-beneficial care near the end of life, but these conversations are limited in frequency and scope. To address this issue, clinicians are increasingly asked to use standardized medical order forms, like the Medical Orders for Life-Sustaining Treatment (MOLST), to document end-of-life conversations and to help ensure that patients' wishes are realized. In kind, the Centers for Medicare and Medicaid Services recently decided to reimburse physicians as well as nurse practitioners and physician assistants for these conversations. Forty-four percent of physicians and 33.0% of advance practitioners (i.e. survey respondents) reported that they discussed goals of care with all patients with serious, life-limiting illness. Advance practitioners were more likely than physicians to report awareness of MOLST forms, but less likely to feel comfortable making recommendations on end-of-life care... These findings suggest the need to educate physicians and empower APs to facilitate goals of care conversations and use standardized forms, as well as an opportunity for interdisciplinary collaboration. http://goo.gl/jfS1Vr

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. Even less evidence is available to support such well-intentioned private initiatives as the Institute for Healthcare Improvement Conversation Project, the efforts of the Coalition to Transform Advanced Care, the Gundersen Health System's Respecting Choices program, the widely used Five Wishes advance directive of the Aging with Dignity organization, and the services provided by for-profit companies such as Vital Decisions and Common Practice. http://goo.gl/9gFs4X

Related

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 16 June 2016 – 'Advance care planning in England: Is there an association with place of death? Secondary analysis of data from the National Survey of Bereaved People.' Advance care planning (ACP) was found to be strongly associated with lower rates of hospital death and a range of quality outcomes. These findings provide support for the emphasis on ACP in end of life care policy in England, while also suggesting the need for further research to better understand the mechanisms underlying these relationships. http://goo.gl/GgGi36

Hospice palliative care in South Korea: Past, present, and future

KOREAN JOURNAL OF HOSPICE & PALLIATIVE CARE, 2016;19(2):99-108. Hospice palliative care (HPC) in Korea has developed steadily since its introduction in 1965. Currently, it is targeted only towards terminal cancer patients and their families, and the national health insurance scheme covers only inpatient hospice care for said patients. In recent years, healthcare professionals and policy makers have began to recognize the need for HPC services in diverse settings including outside hospital boundaries, and for all terminally-ill patients. A law on HPC passed in January 2016 allows terminally-ill patients to refuse life-sustaining treatments, and will likely facilitate further development of HPC services. It is critical for the government and all interested parties in the medical, academic and social sectors to collaborate to ensure its success once it takes effect in 2017. This article briefly reviews the half-century history of HPC in Korea, and discusses how to prepare for and cope with death and, thereby, improve the quality of death. http://goo.gl/Aa6FL3

The surgical theatre

THE LANCET, 2016;387(10036):2371. The art of medicine has always involved a bit of artifice. The Hippocratic Corpus, the original medical code, warned physicians not to reveal poor prognoses to their patients lest they extinguish their hope. Although medical care has continued to advance, the palimpsest of the Hippocratic mandate has remained visible in professional rules of conduct. Thomas Percival, credited with drafting the first code of medical ethics (1803), believed in benevolent lying as a way to instil optimism in patients. <u>http://goo.gl/zq0FYj</u>

N.B. Selected articles on hope and truth-telling in the context of end-of-life-care are noted in the issue of Media Watch of 14 September 2015, #427 (p.9).

Need for palliative care for neurological diseases

NEUROLOGICAL SCIENCES (Italian Neurological Society) | Online – 14 June 2016 – There is a growing awareness of the importance of palliative care (PC) not only in oncological diseases but also in many other branches of medicine, and it appears particularly evident in the approach to many of the most frequent neurological diseases that are chronic, incurable and autonomy-impairing illnesses. The definition and implementation of palliative goals and procedures in neurology must take into account the specific features of these conditions in terms of the complexity and variability of symptoms, clinical course, disability and prognosis. The realization of an effective palliative approach to neurological diseases requires specific skills and expertise to adapt the concept of palliation to the peculiarities of these diseases; this approach should be realized through the cooperation of different services and the action of a multidisciplinary team in which the neurologist should play a central role to identify and face the patient's needs. It is paramount for the neurologist to be trained in these issues to promote the integration of PC in the care of neurological patients. http://goo.gl/kOQ927

N.B. Selected articles on the palliative care needs of people living with a neurodegenerative disorder are noted in the issue of Media Watch of 16 May 2016, #462 (p.8).

End-of-life care in Hungary

The everyday life of survivors. The quality of life of hospice workers

ORVOSI HETILAP | Online – 10 June 2016 – Each year, the number of hospice services and terminally ill patients increase while the number of hospice workers is falling. The intensification of the physical and mental burdens of the latter can lead to burnout and the fluctuation of the workers Those who filled in the [survey] questionnaire had on average 1.86 workplaces and 45.8% of them reported working 12 or more hours a day. Most often, they suffered from lack of energy (65.1%), disturbing physical pain (46.9%), sleeping (56.9%), and digestion (35%); they considered themselves overweight (56.9%), and they were occupied with work problems even at bedtime (72.8%). Hospice workers are overloaded, they have physical and mental symptoms and they are characterized by compassion fatigue. At the same time, they are also characterized by compassion satisfaction as an ability to accept appreciation for the caretaking. http://goo.gl/8IFZ2d

N.B. Hungarian language article. To access full text click on PDF icon.

Noted in Media Watch, 22 September 2014, #376 (p.14):

ORVOSI HETILAP, 2014;155(38):1504-1509. 'Situation, possibilities and difficulties of the hospice and palliative care in Hungary.' Hospice-palliative care has existed in Hungary for more than 20 years, but physicians know very little about it. At present there are 90 active hospice providers in Hungary, which provide service for more than 8,000 terminally ill cancer patients. There are also problems concerning the attitude and, therefore, patients are admitted into hospice care too late. Hospice care is often confused with chronic or nursing care due to lack of information. http://goo.gl/RXwAfu

N.B. Hungarian language article. To access full text click on PDF icon.

End-of-life care in Canada

Palliative care delivery across health sectors: A population-level observational study

PALLIATIVE MEDICINE | Online - 16 June 2016 - Little population-level information exists about the delivery of palliative care (PC) across multiple health sectors, important in providing a complete picture of current care and gaps in care. In this study, across all health sectors, about half (51.9%) of all decedents received at least one record of (PC) in the last year of life. Being female, middle-aged, living in wealthier and urban neighborhoods, having cancer, and less multi-morbidity were all associated with higher odds of PC receipt. Among 92,276 decedents receiving PC, 84.9% received care in acute care hospitals. Among recipients, 35 mean days of PC were delivered. About half (49.1%) of all PC days were delivered in the last 2 months of life, and half (50.1%) had PC initiated in this

period. Only about one-fifth of all decedents (19.3%) received end-of-life care through publicly funded home care. Less than 10% of decedents had a record of a PC home visit from a physician. http://goo.gl/8Nziwo

Extract from *Palliative Medicine* article

The authors describe methods to capture PC using administrative data. Despite an estimate of overall reach (51.9%) that is higher than previous estimates, they shown that PC is infrequently delivered particularly in community settings and to non-cancer patients and occurs close to death.

Promoting quality care in patients with cancer with limited English proficiency: Perspectives of medical interpreters

PSYCHO-ONCOLOGY | Online – 15 June 2016 – Patients with limited English proficiency are at high risk for lower quality of care, including higher rates of misdiagnoses, medical errors, and serious adverse events. Language barriers and underuse of medical interpreters have been widely identified as obstacles to equitable and quality care; however, the rate of professional interpreter use remains unknown. Further, no known study has explored patients' reasons for refusing interpreter assistance, rather, existing studies have largely focused on physician and parental barriers. Conversations in cancer care often involve complex, confusing, and emotionally laden discussions. In fact, English proficient patients have been shown to have difficulty understanding cancer-related discussions, yet are reluctant to ask questions. In effect, poor communication in cancer care may exacerbate a patient's feelings of helplessness and distrust, which may manifest in treatment non-adherence and care dissatisfaction. http://goo.gl/VSe218

 JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 15 June 2016 – 'Health vulnerability of immigrants with limited English proficiency: A study of older Korean Americans.' Limited English proficiency was identified as a critical source of health vulnerability. Systematic efforts should be made to reach out to older immigrants with LEP and include them in health-related research and prevention and intervention programs. <u>http://goo.gl/Hf9vX9</u>

Selected articles, reports, etc., on the role of interpreters in overcoming language barriers

- JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online 5 November 2015 'Interpreting at the end of life: A systematic review of the impact of interpreters on the delivery of palliative care services to cancer patients with limited English proficiency.' When professional interpreters were not used, patients and families with limited English proficiency had inadequate understanding about diagnosis and prognosis during goals of care conversations, and patients had worse symptom management at the end of life, including pain and anxiety. [Noted in Media Watch, 9 November 2015, #435 (p.15)] http://goo.gl/7gZlvl
- SMITHSONIAN | Online 28 September 2015 'Millions of Americans are getting lost in translation during hospital visits.' Unbeknownst to many patients and physicians, individuals with limited English proficiency have been guaranteed language services under federal law for decades. [Noted in Media Watch, 5 October 2015, #430 (p.4)] <u>http://goo.gl/YKoJve</u>

Cont.

BMC HEALTH SERVICES RESEARCH | Online – 10 September 2015 – 'Overcoming language barriers in healthcare: A protocol for investigating safe and effective communication when patients or clinicians use a second language.' The rising number of migrant patients and foreign-trained staff means that communication errors between a healthcare practitioner and patient when one or both are speaking a second language are increasingly likely. [Noted in Media Watch, 14 September 2015, #427 (pp.6-7)] http://goo.gl/8lseYg

Cancer patients, emergencies service and provision of palliative care

REVISTA DA ASSOCIAÇÃO MÉDICA BRASILEIRA, 2016;62(3). The results of this study proved challenging for service providers and for policymakers. The main types of cancer identified in the emergency could be prevented, diagnosed early, treated and cured. And even in cases with advanced stages, the pain could have been reduced and the family assisted in order to cope with the disease. However, incipient levels of palliative care (PC) and home care services coverage were found, indicating that these services need to be expanded and integrated into early cancer therapy aimed at relieving the suffering of both the patients and their families. http://goo.gl/LZVpqP

N.B. English language article.

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.

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1. Short URLs are used in Media Watch. Links to pdf documents, however, cannot always be shortened.

2. Links are checked and confirmed as active before each edition of the weekly report is distributed.

3. Links often remain active, however, for only a limited period of time.

4. Access to a complete article, in some cases, may require a subscription or one-time charge.

5. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.

6. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

Something Missed or Overlooked?

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

Media Watch: Palliative Care Network-e Website

The website promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <u>http://goo.gl/8JyLmE</u>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- CANADIAN JOURNAL OF CRITICAL CARE NURSING, 2016;27(2):20. 'Physician-assisted death and conscientious objection: Implications for critical care nurses.' In this presentation, the law related to physician-assisted death (PAD) in Canada is examined, with a particular focus on the balancing of patients' right to request PAD when certain criteria are met and health care providers' right to declare a conflict of conscience. Guidance provided to nurses regarding PAD and conscientious objection by federal and provincial legislation, the Canadian Nurses Association Code of Ethics for Registered Nurses, and nurses' regulatory bodies in Canada is discussed. http://goo.gl/0gWzVT
- DEATH STUDIES | Online 10 June 2016 "'A recipe for elder abuse": From sin to risk in antieuthanasia activism.' Anti-euthanasia activists currently make their arguments against physicianassisted dying in terms of vulnerability and risk. Tensions in this strategy emerge because many are drawn to activism out of religious beliefs. This article explains how they have reframed their argument that physician-assisted dying is a "recipe for elder abuse." This strategy attempts to manufacture uncertainty among "vulnerable" groups by strategically deploying doubt against medical institutions and governments, while generating distrust against among family members. This article argues that underlying this strategic deployment of risk are beliefs that posit assisted death as polluting to society. http://goo.gl/kLGONj
- JOURNAL OF THE AMERICAN GERIATRIC SOCIETY | Online 15 June 2016 'From advance euthanasia directive to euthanasia: Stable preference in older people?' People with an advance directive for euthanasia (ADE) were more likely to request euthanasia if they worried about loss of dignity. The majority of older adults who complete an ADE will have a stable preference over time, but an advance desire for euthanasia does not necessarily result in a euthanasia request. Writing an ADE may reflect a person's need for reassurance that they can request euthanasia in the future. http://goo.gl/nm0ngb
- SOJOURNERS UNDERGRADUATE JOURNAL OF SOCIOLOGY, 2016;8:79-93. ""Who owns my life?": Women, legislation, and the right to death.' This paper explores the history of assisted suicide of Canada through a sociological and feminist lens in which it is argued that it has been women who have been the pioneers of decriminalising euthanasia in Canada. This paper will explore the impact women have made on Canadian law in regards to issues surrounding assisted suicide through the following arguments: firstly, that it is mainly women who have to deal with matters of dying with dignity, such as living longer and caring for the elderly; and secondly, that the legislative battle for assisted suicide has taken an extended period of time due to the subordination of women's voices in the legal system. http://goo.gl/jYc55p
 - N.B. The link is to the complete issue of the journal. Scroll down to p.79.

Worth Repeating

Knowing loved ones' end-of-life health care wishes: Attachment security predicts caregivers' accuracy

HEALTH PSYCHOLOGY, 2011;30(6):814-818. Very little is known about the factors that make caregivers more or less accurate as surrogate decision makers for their loved ones. Previous research suggests in low stress situations, individuals with high attachment-related anxiety are attentive to their relationship partners' wishes and concerns, but get overwhelmed by stressful situations. Individuals with high attachment-related avoidance are likely to avoid intimacy and stressful situations altogether. The authors hypothesized both of these insecure attachment patterns limit surrogates' ability to process distressing information and should therefore be associated with lower accuracy in the stressful task of predicting their loved ones' end-of-life (EOL) health care wishes. Surrogates high on either type of insecure attachment dimension [i.e., study participants] were less accurate in predicting their loved ones' EOL health care wishes. It is interesting to note even though surrogates' attachment-related anxiety was associated with lower accuracy of EOL health care wishes of their loved ones, it was associated with higher accuracy in the non-stressful task of predicting their loved ones' everyday living conditions. http://goo.gl/wh8bi8

Media Watch: Online
International
INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: http://goo.gl/hhrU3q
INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <u>http://goo.gl/frPgZ5</u>
PALLIATIVE CARE NETWORK COMMUNITY: <u>http://goo.gl/8JyLmE</u>
PALLIMED: http://goo.gl/7mrgMQ [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]
Asia
ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <u>HTTP://GOO.GL/JNHVMB</u>
SINGAPORE Centre for Biomedical Ethics (CENTRES): <u>http://goo.gl/XrhYCH</u>
Canada
ONTARIO HPC Consultation Services (Waterloo Region Wellington County): http://goo.gl/AhlqvD
Europe
EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <u>http://goo.gl/o7kN3W</u> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]
HUNGARY Hungarian Hospice Foundation: <u>http://goo.gl/5d1l9K</u>
U.K. Omega, the National Association for End-of-Life Care: http://goo.gl/UfSZtu

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