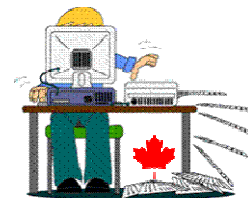


Media Watch...

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

11 January 2016 Edition | Issue #444



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Compiled & Annotated by Barry R. Ashpole

Disparity in healthcare and a social injustice: Scroll down to [Specialist Publications](#) and 'Inadequate palliative care in chronic lung disease: An issue of healthcare inequality' (p.8), In *Annals of the American Thoracic Society*.

Canada

Provide better access to palliative care: Editorial

THE TORONTO STAR | Online – 4 January 2016 – In the din of the debate around doctor-assisted dying, ensuring that patients have the right kind of palliative care (PC) when they need it has unfortunately taken a back seat. But that must change quickly as Canada's population ages. Seniors already outnumber children, and within the next two decades seniors are expected to hit about 25% of the population. That demographic trend is placing a burden on Canada's palliative and home care systems. Already "there are thousands of terminally ill Canadians who are not getting the right kind of care," points out Gabriel Miller of the Canadian Cancer Society. And that is causing patients and families unnecessary suffering. Indeed, Canada's new health minister, Jane Philpott, acknowledges there is evidence only 15% of Canadians have access to high quality PC when they need it. She says the Liberal government is "committed to doing better." That's good news because the lack of PC is dire. According to a damning report last year into Ontario's home care system,¹ not

only are some patients not receiving the PC they need, but others who are receiving it are being forced off it because they don't die fast enough. In the end, Canadians should not have to choose between dying in pain and seeking help through doctor-assisted suicide, when and if that becomes legally available. They should be able to receive good PC as soon as they need it. <http://goo.gl/3P13IQ>

Specialist Publications

'The right to die or palliative care: Mutually exclusive?' (p.15), posted on the Canadian Health Care Network website.

'Physician-assisted death and the anesthesiologist' (p.14), in *Canadian Journal of Anesthesia*.

'Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?' (p.9), in *Clinical Oncology*.

1. '2015 Annual Report' (see 'Community Care Access Centres,' Chapter 3.1 (pp.70-115)), Office of the Auditor General of Ontario, December 2015. [Noted in Media Watch, 7 December 2015, #439 (p.2)] <http://goo.gl/GV7fts>

Cont.

N.B. See '2014 Report,' 'Palliative Care,' Chapter 3.08 (pp.258-288), Office of the Auditor General of Ontario, , December 2014. [Noted in Media Watch, 15 December 2014, #388 (p.2)] <http://goo.gl/aMXj8r>

Noted in Media Watch, 4 January 2016, #443 (p.1):

- THE CANADIAN PRESS | Online – 29 December 2015 – ‘**Debate over assisted suicide should fuel changes to palliative care, advocates say.**’ The escalating debate over doctor-assisted death could be the perfect chance for Canada to fix its broken system of palliative care – a “dark secret” that health advocates say has been quietly deteriorating in the shadows for decades. <http://goo.gl/xdbe1z>

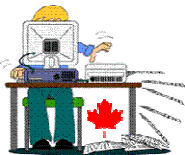
“Elder care is the new child care,” professor says

THE GLOBE & MAIL | Online – 3 January 2016 – For decades, parents have been struggling to juggle work and family, making tradeoffs and seeking special arrangements with employers to attend a school event or pick up a sick child. But as Canada’s population ages and policies encourage the elderly to remain at home, researchers say there is a different kind of work-life balance Canadians need to think about – one that involves a new set of variables. “I would say very clearly elder care is the new child care,” said Linda Duxbury, a Carleton University [Ottawa, Ontario] business professor who has spent her career researching work-life balance... Her findings to date are sobering. In a sample of 25,000 mostly professional workers, 70% said they are responsible in some way for the care of an elderly relative or friend and about half said they are caring for two or more seniors. On average, those responsibilities last for more than six years – far longer than the weeks or months of leave provided by employer and government programs. Professor Duxbury’s research shows looking after an aging or ill family member or friend is much different than raising a child. Re-

searchers point to a convergence of factors that are making matters worse. The much-discussed greying of Canada’s population means there are an increasing number of elderly who require care, but the issue doesn’t stop there. People are having fewer children later in life, meaning there are fewer siblings to share the duties of helping elderly parents and increasingly they are being asked to do it when they have young children – the so-called “sandwich generation” – and while they are in the middle of their careers. <http://goo.gl/4BBAUR>

Over one-quarter of caregivers “sandwiched”

2.2 million Canadians could be considered “sandwiched” between caregiving and raising children. Most are women between the ages 35 and 44, and are helping their parents or parents-in-law, while also having at least one child under 18 living at home. ‘Caregivers in Canada, 2012’ Statistics Canada [Noted in Media Watch, 16 September 2013, #3323 (p.1)] <http://goo.gl/V6MyJ0>



[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>

[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.14.

U.S.A.

Palliative care cuts costs for cancer patients with other health problems

U.S. NEWS & WORLD REPORT | Online – 8 January 2016 – Palliative care (PC) reduces hospital costs for incurable cancer patients who have other serious health conditions, a new study says.¹ Previous research has found a link between PC and lower health care costs, but this is the first study to focus on patients with multiple health issues, the researchers said. The study included terminally ill cancer patients with a number of co-existing chronic conditions (comorbidities). When they were admitted to the hospital, some were seen by a PC team while others received usual care. Hospital costs for those in the PC group were 22% lower than for those in the usual care group. Also, costs were up to 32% lower for PC patients with the greatest number of health problems... “We already know that coordinated, patient-centered PC improves care quality, enhances survival, and reduces costs for persons with cancer,” said study

lead author Dr. R. Sean Morrison, professor of geriatrics and palliative medicine at the Icahn School of Medicine at Mount Sinai in New York City. “Our latest research now shows the strong association between cost and the number of co-occurring conditions. <http://goo.gl/7TT0xf>

Specialist Publications

‘Hospice admission assessment: A narrative view’ (p.7), in *American Journal of Hospice & Palliative Medicine*.

‘Health care preferences among nursing home residents: Perceived barriers and situational dependencies to person-centered care’ (p.7), *Journal of Gerontological Nursing*.

1. ‘Palliative care teams’ cost-saving effect is larger for cancer patients with higher numbers of comorbidities,’ *Health Affairs*, 2016;35(1):44-53. <http://goo.gl/WvU7mr>

Noted in Media Watch, 22 June 2015, #415 (p.9):

- *THE LANCET ONCOLOGY* | Online – 18 June 2015 – **‘Early in-patient palliative care consultation saves costs.’** A new study has shown early in-patient palliative care consultation – with its focus on symptom management, psychosocial support, and advanced care planning – has the added benefit of substantial cost savings for hospitals.¹ <http://goo.gl/UuohSx>

1. ‘Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: Earlier consultation is associated with larger cost-saving...’ *Journal of Clinical Oncology*, 8 June 2015. [Noted in Media Watch, 15 June 2015, #414 (p.5)] <http://goo.gl/3ZZHbU>

A palliative care doctor weighs California’s new aid-in-dying law

CALIFORNIA | National Public Radio – 4 January 2016 – When she first heard California’s new aid-in-dying law was signed, Dr. Carin van Zyl was relieved to hear assisted death would be an option for her if she ever needed it herself. But as a palliative care (PC) doctor at the University Of Southern California Keck School Of Medicine, she’s worried that the law might lead people to consider lethal medications over other options that may better accommodate their wishes. “Patients feel as though their choices are between untreated suffering or physician-assisted suicide,” she told NPR... “Palliative medicine, when it’s applied skilfully and at the right time, often relieves most of the suffering that prompts people to ask for [death] in the first place,” she says. But PC ... isn’t available to everyone... There are smaller hospitals that don’t have palliative medicine teams, and it may be hard to get treatment even in urban areas. Van Zyl thinks more work should be done to make palliative medicine more accessible. “I worry we make [lethal medication] available before we put the necessary effort forward,” she says. Not everyone can be helped with PC, van Zyl says, and some people truly would have benefited from the aid-in-dying law had it been passed earlier. “I think about those patients all the time. I do recall a patient who understood that his death would be sudden and unpredictable and likely quite painful.” <http://goo.gl/CecXES>

Cont.

Noted in Media Watch, 7 December 2015, #439 (p.5):

- CALIFORNIA | *Kaiser Health News* – 1 December 2015 – ‘**Aid-in-dying laws only accentuate need for palliative care, providers say.**’ Palliative care (PC) doctors say the law underscores the need to raise awareness among doctors and patients about what they do and to expand access to high-quality programs. A recent report by the California HealthCare Foundation showed that residents in 22 of 58 California counties don’t have access to community-based PC, and those in 19 counties don’t have access to in-patient programs.¹ Foundation researchers also found recently that specialists are in short supply and that there is no reliable way to pay for such care. <http://goo.gl/WNicm9>
1. ‘Dying in California: A Status Report on End-of-Life Care,’ California HealthCare Foundation and the Coalition for Compassionate Care, October 2015. [Noted in Media Watch, 26 October 2015, #433 (p.2)] <http://goo.gl/VxeDb7>

International

End-of-life care in Australia

Seeking a home close to the end

AUSTRALIA (Victoria) | *The Bendigo Advertiser* – 9 January 2016 – The state government says central Victorians will soon have access to better end-of-life care (EOLC). A Department of Health & Human Services spokesperson said consultation about improving care and support for patients and carers took place late last year. “The government is developing a new state-wide EOLC framework that will ensure all Victorians have access to the best quality end-of-life care,” the spokesperson said. “The government supports quality EOLC that relieves pain and suffering, and provides empowering support to family, friends and carers.” It comes amid concerns that it is difficult to find accommodation for patients stuck between acute hospital treatment and end-of-life hospice care. <http://goo.gl/X6HeBT>

Noted in Media Watch, 25 May 2015, #411 (p.7):

- AUSTRALIA (Victoria) | ABC News (Melbourne) – 18 May 2015 – ‘**Dying at home: Thousands of Victorians unable to receive community-based palliative care, while hospitals attract funding.**’ A recent auditor-general report into palliative care found that 70% of terminally ill Victorians wish to die at home, yet only 14% do.¹ <http://goo.gl/1YnTb>
1. ‘Palliative Care,’ Victorian Auditor-General, 2015 [Noted in Media Watch, 2015, #406 (p.5)] <http://goo.gl/XAcDmQ>

Noted in Media Watch, 6 October 2014, #378 (p.7):

- AUSTRALIA (Victoria) | Grattan Institute (Melbourne) – September 2014 – ‘**Dying well.**’ Despite widespread assumptions about the cost of end-of-life care, only about \$5-billion a year is spent on the last year of life for older people in a health budget of \$100-billion. But only about \$100-million is spent on helping people to die at home. <http://goo.gl/oGsqgT>

British people donating bodies to science to avoid funeral costs

U.K. | *The Daily Telegraph* – 8 January 2016 – A leading forensic anthropologist said giving remains to anatomy departments can be seen as a way of avoiding the burden of funeral costs. However, science departments are not always able to take a person’s body, because of disease or because there is simply no space. Professor Sue Black, Director of the Centre for Anatomy & Human Identification at the University of Dundee, told the bereavement benefits inquiry families can be shocked to realise their loved one’s remains cannot be donated. “It is important that bequeathal is not viewed as an option to address funeral poverty although for some individuals it is unquestionably used in this manner,” she said. The Work & Pensions Committee is investigating funeral poverty... <http://goo.gl/aU7Ygf>

Cont.

Noted in Media Watch, 7 December 2015, #439 (p.7):

- U.K. | BBC News – 30 November 2015 – **“Paupers’ funerals” cost councils £1.7 million.** The cost to local councils of so-called “paupers’ funerals” has risen almost 30% to £1.7 million in the past four years. The number of these funerals has risen by 11%, a Freedom of Information request by BBC Local Radio revealed. <http://goo.gl/hYWfll>

End-of-life care in England

University carer alert system wins recognition in end-of-life care report

U.K. (England) | Care Appointments – 6 January 2016 – A university-developed alert system, designed to assess the needs of people caring for terminally ill loved ones, has featured prominently in a recently published ... report.¹ The Carers’ Alert Thermometer (CAT), produced by researchers from Edge Hill University, is a simple screening tool which was developed with more than 245 carers and professionals from around the North West and aimed to provide an alert to potential areas of burden that carers are experiencing, and trigger interventions where appropriate. The CAT is a response to a major research study which found that support received by unpaid family carers could be a significant factor in what happens to terminally ill people, particularly those with cancer, at the end of their lives.² <http://goo.gl/HiZE2p>

1. ‘Better Endings: Right care, right place, right time,’ National Institute for Health Research, December 2015. <http://goo.gl/1CYmDi>
2. ‘Development of the Carers’ Alert Thermometer (CAT) to identify family carers struggling with caring for someone dying at home: A mixed method consensus study,’ *BMC Palliative Care*, 3 May 2015. <http://goo.gl/7lp1hl>

N.B. National Health Service England’s first strategy for end-of-life care (EOLC), published in 2008, has succeeded in reversing the trend of increasing the proportion of deaths taking place in hospital. Many people will continue to die in hospitals, however, sometimes by their own choice, sometimes by necessity of the circumstances leading up to their death. A revised version of ‘Transforming EOLC in acute hospitals: The route to success “how to” guide,’ was published in December 2015. <http://www.nhs.uk/resource-search/publications/eolc-rtis-how-to-acute-hospitals.aspx>

End-of-life care in London

U.K. (England) | London Councils – 4 January 2016 – End-of-life care and support services provided in London have been improving and becoming increasingly integrated, however, the capital still faces a number of challenges. Despite the majority of people saying they would prefer to die in their own home, London has the highest proportion of people dying in hospital of all English regions. Between 2011 and 2013, 49% of deaths in England occurred in hospital compared to 55% in London. London has the highest average length of hospital stay for people with a terminal illness compared to other regions in England. The 2011 national VOICES survey of bereaved relatives rated overall quality of care across all services lower in London than in any other part of the country.¹ The capital’s population aged 65+ is projected to rise to over

1.5 million by 2041. With people living longer and with more complex health needs, an increase in demand for palliative care (PC) is expected. In London, less than half of the people who have PC needs actually receive that specialized care. In 2014, over two thirds of hospital specialist PC services and over a third of community specialist palliative services were not funded to provide 24/7 telephone advice and 9 to 5, seven days a week face-to-face visiting. <http://goo.gl/XS9jYB>

Specialist Publications

‘Care of the dying adult: A time for hope’ (p.12), in *The Lancet*.

1. ‘The National Bereavement Survey (VOICES) 2011,’ Office for National Statistics (for the Department of Health), July 2012. <http://goo.gl/E4JrDA>

Cont.

Noted in Media Watch, 26 October 2015, #433 (p.6):

- U.K. (England) | Pan-London End of Life Alliance – 19 October 2015 – ‘**Is London the worst place to die?**’ A report by the Economist Intelligence Unit ranked the U.K. as the best country in the world for end-of-life care (EOLC) services.¹ However, the quality of EOLC received in London currently underperforms against national averages.² The London Assembly Health Committee will examine EOLC in the capital and the barriers certain groups face. <http://goo.gl/rMvweZ>
 1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf
 2. ‘A review of specialist palliative care provision and access across London,’ London Cancer Alliance, PallE8 & Marie Curie, 18 September 2015. [Noted in Media Watch, 21 September 2015, #428 (p.5)] <https://www.mariecurie.org.uk/globalassets/media/documents/research/london-spc-provision-report.pdf>

South Korea delays approval of death with dignity bill

SOUTH KOREA | *The Korea Herald* (Seoul) – 3 January 2016 – Uncertainties loom over whether the nation’s death with dignity bill will be passed before the current parliamentary term ends after the general elections in April. South Korea’s parliamentary committee ... delayed its approval of the so-called “well-dying” bill – which allows patients with incurable diseases to end their own lives by rejecting any life-sustaining treatment. The biggest stumbling block is the ongoing debate among lawmakers on whether or not traditional Korean doctors should also be allowed to participate in treatment at hospices. All pending bills are automatically discarded after parliamentary term ends, so it remains unclear whether the bill will be passed at all. <http://goo.gl/Vcf3zY>

Noted in Media Watch, 14 October 2013, #327 (p.9):

- *CRITICAL CARE* | Online – 4 October 2013 – ‘**Survey of controversial issues of end-of-life treatment decisions in South Korea: Similarities and discrepancies between healthcare professionals and the general public.**’ Over 50% of survey respondents thought that end-of-life treatment decisions should be made through discussions between the physician and the patient’s family. For conflict resolution, 75% of South Koreans not working in healthcare preferred direct settlement between the medical staff and the patient’s family, while 55% of healthcare professionals preferred the hospital ethics committee. <http://goo.gl/QRuuY6>

N.B. South Korea was ranked 18th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit, October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)] <http://goo.gl/bT3PV5>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- THE NETHERLANDS | NL Times – 7 January 2016 – ‘**Euthanasia ok’d for dementia patients who request it when lucid.**’ The Ministries of Public Health & Security and Justice updated their “guide” on euthanasia to give people suffering from severe dementia the option of euthanasia, even if they are unable to express the wish themselves. This is only possible if the patient wrote a declaration with his wish for euthanasia while he was still clearheaded... The new guide states that patients with severe dementia often do not seem to be suffering unbearably under their dementia, but they do suffer under the physical conditions that go along with it, such as severe anxiety and pain. “In those cases a doctor may give euthanasia, even if a patient can not make it clear in words or gesture. But there has to be a written request for euthanasia, that the patient drew up earlier.” The guide was updated to take away the uncertainty about the possibilities for euthanasia in dementia patients. According to the guide, doctors have given euthanasia to dementia patients with a previously written request a few times before. But if it is unclear whether such a request still exist at a time that a patient is unable to express himself, chances are that the doctor will not carry out euthanasia. <http://goo.gl/fMX4bK>

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

Patient- and family-centered care: It's not just for pediatrics anymore

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2016;18(1):40-44. Patient- and family-centered care (PFCC) is changing the way hospitals provide patient care, increasing staff satisfaction, decreasing costs, and improving patient outcomes. Although hospitals make unique, organization-specific PFCC principles, all of them tend to endorse similar core values by recognizing the importance of family members' roles in individual patients' health care experience, establishing relationships with and supporting patients and families, and helping patients discover how their own strengths and weaknesses influence their health and health care. When patients' needs are prioritized, they engage in treatment and the treatments are more effective. Hospitals where PFCC is part of the organizational culture find not only that patient, family, and staff satisfaction ratings significantly increase, but also that patients' health outcomes improve. Implementation of PFCC is also correlated with a decrease in patients' emergency department visits, faster recovery, and decreased utilization of health care resources. PFCC has become widespread throughout health care. The PFCC concepts of *patient-physician collaboration* and *treating the patient as a whole person* are not new. <http://goo.gl/QO2dlt>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 January 2016 – ‘**Hospice admission assessment: A narrative view.**’ Through a narrative lens, hospice admission assessment can be seen as experiential time and space, where patient's and family's stories are mindfully and deliberately witnessed and explored. Through the practice of narrative mining, the hospice representative can better understand others' offered stories of reality, which will better inform the plan of palliation and hospice care. <http://goo.gl/LuFhwG>
- *BRITISH JOURNAL OF GENERAL PRACTICE* | Online 1 January 2016 – ‘**Rhetoric and reality in person-centred care: Introducing the House of Care framework.**’ The health Foundation describes the four principles of PCC as care that is coordinated, personalised and enabling, and where a person is treated with “dignity, compassion, and respect,” and the Royal College of General Practitioners defines PCC as “...care that is holistic, empowering and tailors support according to the individual's priorities and needs.” These definitions applied to both systems and individuals are not fundamentally different, but they are capable of many different interpretations. <http://goo.gl/4SSH0k>
- *JOURNAL OF GERONTOLOGICAL NURSING* | Online – 29 December 2015 – ‘**Health care preferences among nursing home residents: Perceived barriers and situational dependencies to person-centered care.**’ Interviews were conducted with 255 residents recruited from 35 nursing homes. Analysis identified barriers (i.e., hindrances to the fulfillment of resident preferences) and situational dependencies (i.e., what would make residents change their mind about the importance of these preferences) associated with preferences for using mental health services, choosing a medical care provider, and choosing individuals involved in care discussions. <http://goo.gl/KjJWF3>

[Media Watch: Back Issues](#)

The screenshot displays the IPCRC.NET website. The main header reads "IPCRC.NET International Palliative Care Resource Center". Below the header is a navigation menu with links for Home, About IPCRC, CRR, NCI, Partners, Contact, and Acknowledgments. The page content includes a "GLOBAL PALLIATIVE CARE NEWS ARCHIVE" section, a "MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE" section, and a "Media Watch Archives" sidebar. The sidebar lists back issues from 2014 (July-December, January-June) to 2011 (January-June), plus a "Current" link. The main content area shows a news item titled "MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care" with a download link for the complete issue (PDF, 463 KB).

<http://goo.gl/frPgZ5>

Inadequate palliative care in chronic lung disease: An issue of healthcare inequality

ANNALS OF THE AMERICAN THORACIC SOCIETY | Online – 5 January 2016 – Patients with chronic lung diseases (CLD) suffer higher symptom burden, lower quality of life, and greater social isolation compared to patients with other diagnoses, such as cancer. These conditions may be alleviated by palliative care (PC), yet PC is utilized less by patients with CLD compared to patients with cancer. Underutilization is due, in part, to poor implementation of primary PC and inadequate referral to specialty PC. Lack of primary and specialty PC in patients with CLD falls short of the minimum standard of competent healthcare, and represents a disparity in healthcare and a social injustice. The authors invoke the ethical principles of justice and sufficiency to highlight the importance of this issue. They identify five barriers to implementing PC in patients with CLD: 1) Uncertainty in prognosis; 2) Lack of provider skill to engage in discussions about PC; 3) Fear of using opioids; 4) Fear of diminishing hope; and, 5) Perceived and implicit bias against patients with smoking-related lung diseases. The authors then propose mechanisms for improving implementation of PC for patients with CLD with the goal of enhancing justice in healthcare. <http://goo.gl/KILyIP>

Noted in Media Watch, 27 May 2013, #307 (p.8):

- *THE LANCET RESPIRATORY MEDICINE* | Online – 17 May 2013 – ‘**Palliative care for lung disease: Start early, stay late.**’ Unfortunately, at the end of life when all reasonable curative interventions have failed, many patients with end-stage lung disease still die in pain after much suffering. <http://goo.gl/dVhUON>

Reasons for attempted suicide in Europe: Prevalence, associated factors, and risk of repetition

ARCHIVES OF SUICIDE RESEARCH | Online – 4 January 2016 – As part of the Monitoring Suicide in Europe project, data on 4,683 suicide attempters from nine European countries were collected. Interpersonal conflict was common for all patients except those widowed, living alone, or retired. Mental health problems were prevalent among over 45 year-olds, patients unable to work, and patients with a history of at least three suicide attempts. Financial difficulties were cited more often by patients who were 45-64 years old, divorced or separated, living with children only, and unemployed. Two reasons for suicide attempt, interpersonal conflict and mental health problems, were associated with increased risk of

repetition independent of other factors. Suicide attempters have a multitude of problems of varying prevalence depending on age, gender, and other factors. They present a range of clinical profiles that require a multidisciplinary response. <http://goo.gl/BzCX6W>

Extract from *Archives of Suicide Research* article

Close bereavement, serious illness and own physical illness were associated with [suicide attempters] over 65 years of age.

Noted in Media Watch, 24 March 2014, #350 (p.13):

- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(1):95-105. ‘**Suicide prevention training program for gatekeepers working in community hospice settings.**’ Gatekeepers in community hospice settings encounter patients and caregivers struggling with suicidal thoughts. Limited guidance is available for training staff on the prevention of suicide in hospice care. This study evaluated one promising, evidence-based, suicide prevention program with a behavioral rehearsal practice session. <http://goo.gl/WVJYhx>

Noted in Media Watch, 17 March 2014, #349 (p.16, under ‘Worth Repeating’):

- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. ‘**Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.**’ Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a “desire to die” statement, underpinned by key principles of therapeutic communication and a review of empirical literature. <http://goo.gl/oEkZWH>

Inappropriate prescribing of preventative medication in patients with life-limiting illness: A systematic review

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 5 January 2016 – Patients with life-limiting illnesses are prescribed preventative medications considered inappropriate in the context of diminished life expectancy. The way in which preventative medication appropriateness is assessed in patients with life-limiting illness varies considerably – with some methodologies utilising criteria previously developed for elderly populations. Given this lack of standardisation, improving the prescribing in this context requires an approach specifically designed and validated for populations with life-limiting illness. <http://goo.gl/rhYmzW>

Prognosis, treatment benefit and goals of care: What do oncologists discuss with patients who have incurable cancer?

CLINICAL ONCOLOGY | Online – 14 December 2015 – The authors describe documentation of prognosis, treatment benefit and goals of care discussions in outpatients with advanced cancer. 222 patients were included [in this study]: 80% (177/222) with lung cancer and 20% (45/222) with pancreas cancer. Medical oncology notes documented discussion of prognosis in 64% (142/222), palliative intent of therapy in 82% (182/222), magnitude of treatment benefit in 29% (64/222) and goals of care in 4% (9/222) of patients. An estimate of survival was documented in 36% (79/222) of cases. Across medical oncology providers there was substantial variation in the frequency of discussing prognosis (range 33-90%), treatment intent (range 55-100%), and goals of care (range 0-17%). In total, 41% (93/222) of patients were seen by palliative care (PC); substantial medical oncology provider variation was observed (range 27-58%). Referral rates to PC did not increase over time (41-44%). In this cohort of ambulatory patients with an estimated life expectancy of 1 year or less, medical oncology documentation of prognosis, treatment benefit and goals of care was poor. Less than half the patients were seen by PC. Initiatives to improve documentation and referral to PC are needed. <http://goo.gl/W7iooz>

Noted in Media Watch, 12 October 2015, #431 (p.4):

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 5 October 2015 – ‘**Outcomes of prognostic disclosure: Associations with prognostic understanding, distress, and relationship with physician among patients with advanced cancer.**’ Prognostic disclosures are associated with more realistic patient expectations of life expectancy without decrements to their emotional well-being or the patient-physician relationship. <http://goo.gl/N2v1vZ>

Related

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 8 January 2016 – ‘**ICU deaths in patients with advanced cancer: Reasonable criteria to decrease potentially inappropriate admissions and lack of benefit of advance planning discussions.**’ Incorporating proposed admission criteria in ICU admission guidelines may prevent 37% of inappropriate, advanced cancer admissions to the ICU. A simple increase in numbers of advance planning discussions would not likely change significantly the numbers of inappropriate ICU admissions. <http://goo.gl/7R3y8Q>

Integrating the complementary skills of palliative care and cardiology to develop care models supporting the needs of those with advanced heart failure

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE | Online – 4 January 2016 – As therapies become increasingly sophisticated, even patients suffering from a single disease are rarely treated by one specialist. Nowadays, it is normal practice for a patient with advanced heart failure to be seen by several doctors, e.g., a general cardiologist, electrophysiologist, interventionist, heart failure specialist and, when needed, representatives from other departments, e.g., an anesthesiologist prior to surgery. Although the idea of holistic needs assessment promoted by palliative care (PC) and the impact of the implementation of PC on both patients’ comfort and survival has been described, the involvement of PC remains unusual. <http://goo.gl/7QMeYR>

Cont.

Noted in Media Watch, 13 July 2015, #418 (p.10):

- *AMERICAN HEART JOURNAL* | Online – 2 July 2015 – ‘**Unique challenges of hospice for patients with heart failure: A qualitative study of hospice clinicians.**’ This study suggests potential opportunities for hospice clinicians and referring providers who seek to collaborate to improve care for patients with heart failure during the transition to hospice care. <http://goo.gl/cJPDp0>
- *BRITISH JOURNAL OF CARDIAC NURSING* | Online – 3 July 2015 – ‘**Understanding palliative care needs in heart failure.**’ Clinicians often struggled to discuss palliation with heart failure patients owing to the unclear disease trajectory and cardiac-specific barriers to identifying palliation needs. <http://goo.gl/nXUada>
- *HEART FAILURE CLINICS*, 2015;11(3):479-498. ‘**Team-based palliative and end-of-life care for heart failure.**’ Clinical practice guidelines endorse the use of palliative care (PC) in patients with symptomatic heart failure. The optimal content and delivery of PC interventions remains unknown and its integration into existing heart failure disease management continues to be a challenge. <http://goo.gl/tiqhX>

N.B. Additional articles on palliative care in patients with heart failure noted in past issues of Media Watch are listed in the issue of the weekly report of 19 January 2015, #393 (pp.11-12).

One of society’s most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deafblind people

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 5 January 2016 – Twenty-eight references were identified for inclusion, originating from the U.K., U.S., Australia, Continental Europe and the Nordic Countries. No empirical studies specifically examining the experience of vulnerability of deafblind people were found. However, deafblind people describe feelings of vulnerability in studies exploring their experiences more generally, and in personal accounts of living with the impairment. Literature produced by practitioners and specialist organisations also explores the topic. Deafblind people are identified as a population “at risk” of various adverse outcomes, particularly when compared to the non-deafblind majority, and deafblind people describe being and feeling vulnerable in various situations. The literature largely relates to negative outcomes and includes significantly less exploration of positive risk taking, coping capacity and resilience. <http://goo.gl/KprD7r>

Selected articles on hearing loss in palliative care

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 13 April 2015 – ‘**Hearing loss in palliative care.**’ Despite its high prevalence, there is remarkably little written on the impact of hearing loss in the palliative care literature. The authors describe simple methods of screening patients for hearing loss, and suggest that practical approaches should be used universally in patient encounters. These include facing the patient, pitching one’s voice low, using a pocket talker, and creating a hearing-friendly environment when planning a family or group meeting. [Noted in Media Watch, 20 April 2015, #406 (p.11)] <http://goo.gl/RKJGbh>
- *JOURNAL OF PALLIATIVE CARE*, 2012;28(2):105-112. ‘**Palliative and end-of-life care in Newfoundland’s deaf community.**’ Key findings [of this Canadian study] indicate the deaf community has limited understanding of their options for palliative and end-of-life care. [Noted in Media Watch, 13 August 2012, #266 (p.6)] <http://goo.gl/FTDz2b>
- *HEC FORUM*, 2002;14(3):197-208. ‘**American Sign Language and end-of-life care: Research in the deaf community.**’ The authors describe a community-based participatory research process used to develop a means of discussing end-of-life care needs of deaf seniors. [Noted in Media Watch, 20 August 2012, #267 (p.12, under ‘Worth Repeating’)] <http://goo.gl/y1F4fe>

Anticipatory grief: An evidence-based approach

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2016;18(1):15-19. Anticipatory grief is a symptom that can be experienced by caregivers and patients, especially those coping with advanced disease. Frequently, symptoms of anticipatory grief are disguised as depression, anxiety, or pain. This article reviews the concept of anticipatory grief, explores various assessment tools, and offers communication-based management strategies. Key nursing implications are also discussed. <http://goo.gl/fECilt>

Noted in Media Watch, 11 August 2014, #370 (p.11):

- *INTERNATIONAL JOURNAL OF PSYCHOTHERAPY*, 2014;18(2):72-79. **‘The truth shall set you free: Saying an honest “goodbye” before a loved-one’s death.’** This article ... reviews some of the relevant literature, defines the premise of “unfinished business,” describes the therapeutic benefits of fantasy, and provides a case example using the “empty chair” method. The psychotherapy described is about creating an opportunity for the expression of feelings, making interpersonal contact, and “truth telling” before the other person dies. <http://goo.gl/1QZOkv>

Noted in Media Watch, 24 June 2013, #311 (p.8):

- *AGING HEALTH*, 2013;9(1):103-114. **‘Anticipatory grief therapy for older persons nearing the end of life.’** This article discusses the challenges that anticipatory grief (AG) poses for the older patients, as well as the desired therapeutic outcomes through using this approach. Beneficial therapeutic approaches for AG-related constructs are reviewed, with recommendations to design interventions that target the AG of older patients facing different advanced conditions. <http://goo.gl/93gTEo>

Ethical issues in caring for prison inmates with advanced cancer

JOURNAL OF HOSPICE & PALLIATIVE NURSING | Online – 5 January 2016 – This article includes a discussion of the ethical issues, especially justice issues, encountered in provision of care for prisoners that should, but often does not, approximate that of non-prisoner care. The history of the prison hospice movement is described. The case of a prisoner with extensive cancer and multiple symptoms is presented to highlight the ethical, existential, and practical issues encountered especially by the nurses, as well as other team members providing care for prisoners with advanced cancer. Then follows a discussion of the collaborative, compassionate approach to his care that maintained public and

personal safety while optimizing symptom management and respect for his goals of care. Suggestions for improving care of inmates with serious illness are provided. <http://goo.gl/qVAOzt>

[Prison Hospice Backgrounder](#)

The quality of end-of-life care in the corrections or prison system has been highlighted in Media Watch on a regular basis. An updated compilation of articles, reports, etc., noted in the weekly report was recently posted on the Palliative Care Community Network website: <http://goo.gl/9t8kK3>

[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. <http://goo.gl/8JyLmE>

End-of-life care in England

Care of the dying adult: A time for hope

THE LANCET, 2016;387(10013):2. The National Institute for Health & Care Excellence (NICE) published its first guideline in response to the Neuberger review of the controversial Liverpool Care Pathway (LCP), and the Department of Health's follow-up report.^{1,2,3} The LCP, an algorithm for the physical, psychological, social, and spiritual care of people who were dying, had been widely criticised by the U.K. media and some patients' families for poor implementation, with particular concerns around recognition of when people were dying, and inappropriate use of sedation and hydration. Although around three-quarters of deaths in England each year are expected, our understanding of dying is poor. Recent decades have seen changes in the way people die, from different causes, at older ages with more co-morbidities, and with friends and carers taking on increased importance as family structures have changed. The NICE guideline ... sought to address gaps in understanding by consultation with a wide variety of experts, from palliative care consultants and specialist district nurses to end-of-life (EOL) doulas. The guideline could be criticised as simply repackaging the LCP with changed emphasis on

individualised care instead of the *proforma*, one-size-fits-all approach. But there is something hopeful about this new guideline. With recommendations on how to recognise when someone is dying, communication, shared decision making, and appropriate use of fluids and drugs, the guideline places respect, conversation, and thoughtfulness at the heart of care. It does not address some of the more practical aspects of EOL care, e.g., pain management, and guidelines on implementation are expected in 2017. <http://goo.gl/eaD8CU>

Extract from *The Lancet* article

At a press conference, Gillian Leng, deputy chief executive of NICE, admitted "NICE guidelines always are aspirational in part," but through partnership with the third sector, Royal Colleges, and National Health Service England, and the guideline's recommendations for education and research, these aspirations can and must become reality – not just in the care of those who are dying, but for patients everywhere.

1. 'Care of Dying Adults in the Last Days of Life,' NICE, December 2015. [Noted in Media Watch, 21 December 2015, #441 (p.7)] <https://goo.gl/NKdoxs>
2. 'Review of Liverpool Care Pathway for Dying Patients,' Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://goo.gl/bCg4UY>
3. 'One Chance to Get it Right: Improving People's Experience of Care in the Last Few Days and Hours of Life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://goo.gl/bCg4UY>

The changes of ethical dilemmas in palliative care a lesson learned from comparison between 1998 and 2013 in Taiwan

MEDICINE (Baltimore), 2016;95(1):e2323. All [survey] participants took a questionnaire to survey the "frequency" and "difficulty" of 20 frequently encountered ethical dilemmas, which were grouped into four domains by factor analysis. All of the highest-ranking ethical dilemmas in 2013 were related to insufficient resources. Physicians with less clinical experience had a higher average "ethical dilemma" score in clinical management. Physicians with dissatisfaction in providing palliative care (PC) were associated a higher average "ethical dilemma" score in communication. Nurses reported higher "ethical dilemma" scores in all items of resource allocation in 2013. Further analysis confirmed that, in 2013, nurses had a higher average "ethical dilemma" score in resource allocation after adjustment for other relating factors. PC nursing staff in Taiwan are more troubled by ethical dilemmas related to insufficient resources than they were 15 years ago. <http://goo.gl/Pa1jPN>

The “good death”: An integrative literature review

PALLIATIVE & SUPPORTIVE CARE | Online – 6 January 2016 – The “good death” is a dynamic concept and has evolved over time to become a “revivalist” good death: a planned, peaceful, and dignified death, at home, surrounded by family members. As the “good death” continues to evolve, the key questions are: How do cultural perceptions of death and dying change? What are the forces that shape Western attitudes and beliefs around death and dying? And how does the “good death” discourse frame the dying experience in contemporary society? The purpose of this manuscript is to describe the underlying discourse in the literature on the “good death” in Western societies. Four main themes emerged from reviewing 39 articles on the “good death”: 1) The “good death” as control; 2) The wrong “good death”; 3) The threatened “good death”; and, 4) The denial of dying. Evolving in response to prominent social attitudes and values, the contemporary “good death” is a powerful, constraining discourse that limits spontaneity and encourages one way to die. Social, political, and demographic changes now threaten the stability of the “good death”; dying is framed as an increasingly negative or even unnecessary process, thus marginalizing the positive aspects of dying and rendering dying absent, invisible. <http://goo.gl/NCthtU>

Selected articles on defining “a good death”

- *JOURNAL OF PALLIATIVE CARE*, 2015;31(3):158-165. ‘**Defining a good death: A deliberative democratic view.**’ Many attempts to define a good death have been recorded in the academic literature. In most of these attempts, the methods used have been surveys, interviews, and focus groups. These methods have yielded important information, but they have failed to provide an opportunity for public deliberation, whereby people engage collectively with an issue, consider it from all sides, and struggle to understand it. The authors ... paint a picture that differs from those painted by the previous research, which focused mainly on individual and idealized views of a good death. [Noted in Media Watch, 7 September 2015, #426 (p.14)] <http://goo.gl/lcpZRT>
- *SUPPORTIVE CARE IN CANCER* | Online – 7 September 2014 – ‘**Correlates of a good death and the impact of hospice involvement: Findings from the national survey of households affected by cancer.**’ Enhanced provider training/communication, referrals to hospice and greater attention to symptom management may facilitate improved quality of dying. [Noted in Media Watch, 15 September 2014, #375 (p.8)] <http://goo.gl/7kbfIK>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 February 2012 – ‘**Concept analysis of good death in terminally ill patients.**’ The findings of this study describe the evolution of the good death concept over time from the prehistoric era followed by pre-modern, modern, and post-modern times. General attributes of a good death include pain and symptom management, awareness of death, patient’s dignity, family presence, family support, and communication among patient, family, and health care providers. [Noted in Media Watch, 27 February 2012, #242 (p.9)] <http://goo.gl/LuncFG>

Public health approaches to palliative care – The progress so far

PROGRESS IN PALLIATIVE CARE | Online – 6 July 2016 – This article discusses four broad questions often asked about the public health approach to palliative care (PC): 1) What is the evidence for the effectiveness of the approach?; 2) Will this approach embedded inside PC services deliver the kinds of social changes needed to address the social epidemiology of living with life-limiting illness, long term caregiving and grief and bereavement?; 3) Is recent interest in this approach simply all about cost-savings for governments?; and, 4) Will an emphasis on health promotion and community development subtract from efforts to increase or maintain clinical supports at the end of life? <http://goo.gl/OQmVbh>

End-of-life care in France

The decision to withhold and withdraw active treatments, an ethical approach

SOINS: LA REVUE DE RÉFÉRENCE INFIRMIÈRE, 2015;60(801):49-51. Intensive care medicine is confronted with situations of suffering and dependence experienced as the appropriation of the body or medical futility. In this context, withholding and withdrawing active intensive care must be given a framework. The ethical challenge is to decide to continue or not with care considered vain or futile. The 'Leonetti Law,' in particular, helps to clarify the situation for professionals and families. <http://goo.gl/mWYjJi>

N.B. French language article. The Léonetti Law Act (2005) established the right to "let die." The law opposes the "unreasonable obstinacy" of undertaking or continuing "unnecessary or disproportionate" treatment, "with no other effect than maintaining life artificially."

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN JOURNAL OF ANESTHESIA* | Online – 6 January 2016 – '**Physician-assisted death and the anesthesiologist.**' This paper highlights other countries' experiences with physician assisted death (PAD) in order to shed light on this question and to forecast issues that Canadian physicians will face once the change to the law comes into effect. At present, there is no legislative scheme in place to regulate the conduct of PAD. Physicians and their provincial colleges may find themselves acting as the *de facto* regulators of PAD if a regulatory vacuum persists. With their specialized knowledge of pharmacology and interdisciplinary leadership, anesthesiologists may be called upon to develop protocols for the administration of PAD as well as to administer euthanasia. Canadian anesthesiologists currently have a unique opportunity to consider the complex ethical issues they will face when PAD becomes legal and to contribute to the creation of a regulatory structure that will govern PAD in Canada. <http://goo.gl/7J9v3a>

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International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://goo.gl/Ws2Yv8>

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>

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>

- CANADIAN HEALTH CARE NETWORK | Online – 5 January 2016 – ‘**The right to die or palliative care: Mutually exclusive?**’ The basic argument against the right to die legislation, or the right for assisted suicide, seems to rest with our often poor approach to palliative care (PC) and to hospice. Without a doubt, there are some fabulous PC and hospice facilities and programs in Canada. I worked at one such facility here in the Montreal area. The staff was knowledgeable, kind, and understanding to both patients and family members. The problem is, programs like this are few and far between across our country. In 2007, I wrote an article for the CBC about the difficulty in accessing palliative and hospice care several years ago, and I wrote: “Despite the benefits of PC to patients and their families, 75% to 85% of the 160,000 Canadians who die from terminal illnesses each year don’t have access to it during the end-of-life stage, according to statistics from a Senate report published in 2000 and the Canadian Hospice Palliative Care Association.² If you live in an urban area or are hospitalized in a big city, your chances of being offered PC services are generally higher than those who are in Canada’s rural areas.” It seems not much has changed today.

1. Palliative care: Raising awareness key to improving access,' CBC News, 5 December 2007.
<http://goo.gl/4bCUNc>

2. 'Quality End-of-Life Care: The Right of Every Canadian,' Subcommittee to update 'Of Life and Death' of the Standing Senate Committee on Social Affairs, Science & Technology., 2000.
<http://goo.gl/b1e4KT>

N.B. Access to the Canadian Health Care Network requires a subscription. Network home page:
<http://goo.gl/EtOqGI>

[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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[Links to Sources](#)

Updated 01.11.2016

1. Short URLs have been introduced with this issue of Media Watch, hopefully, in order to improve access to articles, reports, etc. 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.

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