

Media Watch...

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

14 December 2015 Edition | Issue #440



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Patient centred care: Scroll down to [Specialist Palliative Care](#) and ‘How to get better care with lower costs? See the person, not the patient’ (p.8), in *Journal of the American Geriatrics Society*.

Canada

Psychosocial aspects of end-of-life care

Cachexia: The last illness

NATURE | Online – 9 December 2015 – As a palliative care researcher, Susan McClement has talked to many people dying of cancer and their families – and some of their stories are burned into her brain. One man was so concerned by the sight of his emaciated wife, whose body had been ravaged by metastatic breast cancer, he resorted to force feeding her – pinching her nose and slipping in a spoonful of food when she opened her mouth. Convinced food would give her the energy to fight the cancer, his daily visits became protracted battles. She died a few weeks later. McClement ... [a professor at the faculty of nursing and a research associate at the Manitoba Palliative Care Research Unit] ... says nutritional conflicts can become a source of regret for relatives. The woman in this case had cachexia, a metabolic disorder that affects some 9 million people worldwide, including as many as 80% of people with advanced cancer. It typically involves extreme weight and muscle loss, makes routine activities difficult, and increases the risk of deadly complications such as infections; adding calories doesn't reverse cachexia. The dis-

order sometimes provokes extreme reactions from family members because it serves as visual confirmation of their worst fears. Cachexia is seen in the late stages of almost every major chronic illness, affecting 16-42% of people with heart failure, 30% of those with chronic obstructive pulmonary disease, and up to 60% of people with kidney disease. For many years it was overlooked, as physicians and researchers focused their attention on the primary illness instead. <http://www.nature.com/news/cachexia-the-last-illness-1.18961>

Extract from the *Nature* article

McClement ... has been interviewing more families of people with cachexia. She hopes to find ways to better inform them about the condition and help them to cope. Given the absence of pharmacological interventions, such psychosocial ones are important, she says. “That’s all we’ve got.”

Cont.

Noted in Media Watch, 19 December 2011 #237 (p.12):

- *PSYCHO-ONCOLOGY* | Online – 8 December 2011 – ‘**Hydration and nutrition at the end of life: A systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff.**’ Decrease in oral intake, weight loss, and muscular weakness in the last phases of a terminal illness, particularly in the context of the cachexia-anorexia syndrome, can be an important source of anxiety for the triad of patient, family, and health staff. The present literature review examines the emotional impact of reduced oral intake as well as perceptions and attitudes toward assisted nutrition and hydration for terminally ill patients at the end of life, among patients, family, and health care staff. <http://onlinelibrary.wiley.com/doi/10.1002/pon.2099/full>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- QUEBEC | *The National Post* – 10 December 2015 – ‘**Is it euthanasia or assisted suicide? Quebec’s end-of-life care law explained.**’ Quebec’s historic Act Respecting End-of-Life Care came into effect, pending an appeal of a Superior Court ruling that could effectively quash the law. In the meantime, it is legal for doctors to administer lethal injections to mentally competent, consenting adults who are at the end of life, have an incurable illness, and experience “constant and unbearable” suffering. <http://news.nationalpost.com/news/canada/is-it-euthanasia-or-assisted-suicide-quebecs-end-of-life-care-law-explained>
- QUEBEC | *The Globe & Mail* – 9 December 2015 – ‘**Time for a transparent debate on assisted suicide.**’ The prospect of a law allowing medically assisted suicide wasn’t mentioned in the [recent Federal] Speech from the Throne, but there is no doubt that this issue will come up some time in 2016. Canada will then, perhaps, follow the path of Quebec and allow, under certain conditions, physicians to provide patients who ask to die with a lethal injection. Let’s hope, though, that the federal government will lead a frank and transparent debate rather than bury the matter under euphemisms and misleading propaganda. The Quebec law on “medical aid in dying” was sold to the public as “the right to die in dignity” – two expressions that many would associate with palliative care (PC) – and this is exactly what Quebecers thought the law was about. Shortly before the law was adopted, an Ipsos survey showed that 40% of respondents did not know the meaning of the word “euthanasia” and that for 51% the law was synonymous with PC or with the cessation of aggressive therapies that artificially prolong the life of a terminally ill patient. Since the issue was obfuscated by both the [province’s] National Assembly and uncritical media, there has not been a real public debate about an issue that has been controversial wherever it has been discussed and that is far from being widely accepted (only four European countries and a handful of U.S. states allow assisted suicide). The rare opponents who dared come out publicly against the “Quebec consensus” were labelled as backward religious zealots, even though most of them were PC specialists with an intimate knowledge of life and death. <http://www.theglobeandmail.com/globe-debate/time-for-a-transparent-debate-on-assisted-suicide/article27653076/>

Specialist Publications

‘**Right to die in Canada: Respecting the wishes of physician conscientious objectors**’ (p.11), in *Canadian Medical Association Journal*.

‘**The critical care perspective in reply to ‘Last rights: Cuthbertson v. Rasouli – What the supreme court didn’t say about end-of-life treatment decisions’**” (p.7), in *Health Law in Canada*.

‘**Physician-assisted death in Canada: As the law changes**’ (p.11), in *Health Law in Canada*.

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.12.

U.S.A.

Hospice care isn't enough for all the dying

CALIFORNIA | *The Sacramento Bee* – 9 December 2015 – People who opposed laws in California, Oregon, Washington, Montana and Vermont authorizing medical aid in dying for terminally ill adults often claim there are better alternatives to relieve suffering. I was one of them. In fact, I served as chief executive officer and chief spokesperson of the Oregon Hospice Association before and after the implementation in 1998 of the nation's first medical aid-in-dying law. I voted against the referendum because I believed it was unnecessary if terminally ill Oregonians had access to high-quality hospice and palliative care (PC). However, I came to realize that it was arrogant of me to believe that hospice and PC professionals could meet all the needs of the dying. Oregon is consistently rated among the best states for providing hospice and PC.¹ Yet, even with the best care, some patients still suffer intolerably and want the option to take prescription medication to die painlessly, peacefully and quickly in their sleep. Other medical professionals also are realizing that terminally ill adults should have access to a full range of end-of-life options. In May, the California Medical

Association dropped its 28-year-long opposition to medical aid in dying, acknowledging that “despite the remarkable medical breakthroughs we've made and the world-class hospice or PC we can provide, it isn't always enough.”
<http://www.sacbee.com/opinion/op-ed/soapbox/article48849635.html>

Specialist Publications

'First-year analysis of a new, home-based palliative care program offered jointly by a community hospital and local visiting nurse service' (p.7), in *American Journal of Hospice & Palliative Medicine*.

'How to get better care with lower costs? See the person, not the patient' (p.8), in *Journal of the American Geriatrics Society*.

'End-of-life care for undocumented immigrants with advanced cancer: Documenting the undocumented' (p.9), in *Journal of Pain & Symptom Management*.

1. 'America's Care of Serious Illness: 2015 State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals,' Center to Advance Palliative Care & National Palliative Care Research Center, September 2015. [Noted in Media Watch, 5 October 2015, #430 (p.14)] <https://reportcard.capc.org/>

Noted in Media Watch, 9 February 2015, #396 (p.9):

- *JOURNAL OF MEDICAL ETHICS* | Online – 3 February 2015 – **'Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience.'** The hypothesis that legal regulation of physician-assisted dying slows development of palliative care is not supported. <http://jme.bmj.com/content/early/2015/02/03/medethics-2014-102116.abstract>

Noted in Media Watch, 31 October 2011, #225 (p.11):

- *BRITISH MEDICAL JOURNAL* | Online – 24 October 2011 – **'Legalisation of assisted dying does not harm palliative care, study concludes.'** The legalisation of assisted dying does not undermine the provision of good palliative care, a report comparing six European countries concludes.¹ <http://www.bmj.com/content/343/bmj.d6779.extract>

1. 'Palliative Care Development in Countries with a Euthanasia Law.' Report by the European Association of Palliative Care for the Commission on Assisted Dying Briefing Papers, October 2011. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/NetCache/IE/87XQHXCX/PalliativeCareDev/nCWAEuthanasiaLaw.pdf>

U.S. life expectancy flat for third straight year at almost 79

ABC NEWS | Online – 8 December 2015 – A child born last year can expect to make it to age 78 years and 9½ months – the same prediction made for the previous two years.¹ It's not clear why life expectancy has been flat lately, but suicides and fatal drug overdoses probably are playing a role, experts believe. Some researchers have wondered if U.S. life expectancy will peak, due to the nation's obesity problem and other factors. But there's no evidence that's happening now... The U.S. ranks below nearly forty other countries in life expectancy... Japan and Iceland are at the top of that list, at more than eighty-three years. <http://abcnews.go.com/Health/wireStory/us-life-expectancy-flat-straight-year-79-35661474>

1. 'Mortality in the United States, 2014,' Centers for Disease Control & Prevention, December 2015. <http://www.cdc.gov/nchs/data/databriefs/db229.htm>

Related:

- NEWSMAX | Online – 10 December 2015 – **'Skyrocketing chronic disease rates threaten lifespan gains: Report.'** That's the upshot of a report on America's health that warns chronic diseases tied to unhealthy lifestyles are accompanying many Americans into old age.¹ "The major issue is while we are living longer, we are living sicker," says Dr. Rhonda Randall, chief medical officer for United Healthcare Retiree Solutions [and a member of the Scientific Advisory Committee of the United Health Foundation]. <http://www.newsmax.com/Health/Anti-Aging/disease-rates-rise-threaten/2015/12/10/id/705231/>
- 1. '2015 America Health Rankings,' United Health Foundation, Washing DC, December 2015. [file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/UPG4XG0C/2015AHR Annual .pdf](file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/UPG4XG0C/2015AHR%20Annual.pdf)

There aren't enough nursing home beds to meet demand

CNBC NEWS | Online – 7 December 2015 – As baby boomers approach retirement age there will be less and less nursing-home space available. The Census Bureau reported that in 2006 there were 78.6 million boomers in the U.S. Many of them will turn 70 by 2020. By 2030, about 20% of the nation's population will be 65 and over. That compares with 13% right now. So we are aging, and the problem becomes how we will care for all these people. To that point, from 2000 to 2009 the total number of nursing homes in the U.S. decreased by 9%. Additionally, from 2007 to 2011 new construction of nursing-home units decreased by 33%. According to the Department of Health & Human Services, of the 76 million baby boomers heading toward retirement, roughly 70% (about 54 million people) will need some form of long-term care, with close to 13 million of those needing a stay of longer than three years in a skilled nursing facility. <http://www.cnb.com/2015/12/07/there-arent-enough-nursing-home-beds-to-meet-demand.html>

Media Watch: Back Issues



The screenshot shows the IPCRC.NET website. The header includes the site name and navigation links. The main content area features a 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE' section with a 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE' sub-section. A 'Media Watch Archives' sidebar on the right lists back issues from 2011 to 2014. A small article preview is visible at the bottom left of the screenshot.

Media Watch Archives

- 2014, July - December
- 2014, January - June
- 2013, July - December
- 2013, January - June
- 2012, July - December
- 2012, January - June
- 2011, July - December
- 2011, January - June
- Current

<http://www.ipcrc.net/archive-global-palliative-care-news.php>

International

Hospital says sorry for do not resuscitate order on man with Down's syndrome

U.K. (England) | *The Independent* – 8 December 2015 – A hospital that listed a patient's learning disability among reasons for putting a "do not resuscitate" order on his medical file has apologised for breaching his human rights. Relatives of Andrew Waters, who had Down's syndrome, and his carers were not told that medics at Queen Elizabeth the Queen Mother hospital in Margate, Kent, had made the order in 2011, and learned of it by accident after he had been discharged. "When he went home to his residential home his carers were unpacking his bags and they found the DNR in the bag," said Merry Varney, the solicitor who represented the family. Waters, who died in May, aged 53, in circumstances unrelated to the DNR order, had been admitted to hospital in August 2011 for problems related to dementia. Without any prior consultation with his family, staff decided he should not be resuscitated if he developed heart or breathing problems. The reasons listed on the order were: "Downs syndrome, unable to swallow (PEG fed), bed bound, learning difficulties." The order also stated that next of kin were unavailable for consultation, despite relatives making daily visits to Waters in hospital. Waters was discharged weeks later, only to be readmitted the following month when doctors again placed him on a DNR order with no discussion or consultation with the family. It was after his discharge a second time that carers discovered the order. <http://www.theguardian.com/society/2015/dec/08/hospital-says-sorry-for-do-not-resuscitate-order-on-man-with-downs-syndrome>

Noted in Media Watch, 1 October 2012, #276 (p.4):

- U.K. | *The Independent* – 24 September 2012 – '**Do not resuscitate orders: When hospital CPR should not be used.**' The issue of resuscitation has recently brought to the fore following the case of a man with Down's syndrome who was issued with a do not resuscitate order without consent from either himself or from his family. <http://blogs.independent.co.uk/2012/09/24/do-not-resuscitate-orders-when-hospital-cpr-should-not-be-used/>

Elder care in England

Is the Government quietly dropping its promised cap on care costs?

U.K. (England) | *The Daily Telegraph* – 7 December 2015 – Families hoping for a reprieve from the crippling bills they face making sure a loved one is cared for in old age could be in for a bitter blow. Experts believe the long-promised care cap, designed to protect them from "catastrophic" fees, could be scrapped and is unlikely to be introduced in April 2020, as promised in the Autumn Statement. Due to have been launched last April at £72,000, it has already been delayed, but cynicism is growing the scheme will never get the green light – or certainly not in the next five years. Average annual fees range from £19,344 for residential care in the North West to £40,508 for nursing care in the South East, according to health care analysts... <http://www.telegraph.co.uk/finance/personalfinance/insurance/longtermcare/12033507/Is-the-Government-quietly-dropping-its-promised-cap-on-care-costs.html>

End-of-life care in England

Outsourcing care – can the sums add up?

U.K. (England) | BBC News – 4 December 2015 – It was a contract which was centre stage in the debate over outsourcing in the National Health Service (NHS) in England. The £800 million five year deal to run care for older patients and some other adult services in Cambridgeshire was controversial because private contractors bid for it. Then a combination of two NHS trusts won it and now they have decided to throw in the towel. It looks a mess, and has raised many questions over the commissioning and contracting process. The contract covered emergency hospital care, community and mental health for over 65s,

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end-of-life care and some other services for younger adults. During the tender process, which began in 2013, there were protests because the bidders included private sector operators including Virgin and Care UK. But the contract was eventually awarded to a partnership of Cambridgeshire & Peterborough NHS Foundation Trust with Cambridge University Hospitals NHS Foundation Trust. Opponents of outsourcing claimed that £1 million had been wasted on a process which resulted in NHS services staying in the NHS. Now the NHS consortium has decided after barely seven months that it can't make the sums add up. <http://www.bbc.com/news/health-35011894>

Noted in Media Watch, 14 September 2015, #427 (p.14):

- *NURSING TIMES* | Online – 8 September 2015 – ‘**New framework for action on end-of-life and palliative care.**’ A new framework ... has been drawn up by a group of statutory health bodies which is hoped will spur clinical commissioning groups – and health and well-being boards – to make this type of care a priority in local areas.¹ <http://www.nursingtimes.net/nursing-practice/specialisms/end-of-life-and-palliative-care/-new-framework-for-action-on-end-of-life-and-palliative-care/5090142.article>

1. ‘Ambitions for Palliative and End-of-Life Care: A national framework for local action 2015-2020,’ National Palliative & End-of-Life Care Partnership, September 2015. <http://endoflifecareambitions.org.uk/>

Noted in Media Watch, 13 July 2015, #418 (p.8):

- U.K. (England) | National End-of-Life Care Intelligence Network – 6 July 2015 – ‘**End-of-life care profiles for clinical commissioning groups.**’ These profiles ... draw together a wide range of information to give an overview of variations in cause and place of death, by age and sex, for each clinical commissioning group in England. The profiles will help commissioners and providers of end-of-life care get a clearer picture of the end-of-life care needs of their local populations. http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles

N.B. Clinical commissioning groups are National Health Service (NHS) organisations set up under the Health & Social Care Act 2012 to organise the delivery of NHS services in England.

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

Evidence-based practice needed in end-of-life care

THE ASCO POST (American Society of Clinical Oncology) | Online – 10 December 2015 – Evidence-based oncology practice is a systematic approach to problem solving for cancer care providers, characterized by the use of the best evidence currently available for clinical decision-making. Over the past several decades, the oncology community, led by its major organizations such as ASCO and the National Comprehensive Cancer Network, has advanced the implementation of guidelines and other assessment tools to further integrate solid clinical evidence into daily practice, from diagnosis to treatment. However, the delivery of equitable, high-quality end-of-life care has suffered from a lack of study-based evidence. <http://www.ascopost.com/issues/december-10,-2015/evidence-based-practice-needed-in-end-of-life-care.aspx>

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.**’ The disquieting patterns of end-of-life care in the U.S. have been well documented. In the last month of life, one in two Medicare beneficiaries [in the U.S.] visits an emergency department, one in three is admitted to an intensive care unit, and one in five has inpatient surgery. But one of the most sobering facts is that no current policy or practice designed to improve care for millions of dying Americans is backed by a fraction of the evidence the Food & Drug Administration would require to approve even a relatively innocuous drug. <http://www.nejm.org/doi/full/10.1056/NEJMp1509664>

Cont.

Noted in Media Watch, 5 October 2015, #430 (p.10):

- *CANCER BIOLOGY & MEDICINE*, 2015;12(3):193-200. 'Reality of evidence-based practice in palliative care.' The complex multi-morbidity of end-of-life care involves considerations of the patient's physical, psychological, social and spiritual needs. In addition, the field of palliative care covers a heterogeneous group of chronic and incurable diseases no longer limited to cancer. Adequate sample sizes can be difficult to achieve, reducing the power of studies, and high attrition rates can result in inadequate follow up periods. <http://www.cancerbiomed.org/index.php/cocr/article/view/871>

Considerations and recommendations for conducting qualitative research interviews with palliative and end-of-life care patients in the home setting: A consensus paper

BMJ SUPPORTIVE & PALLIATIVE CARE | Online – 8 December 2015 – The authors discuss the views of researchers at an academic palliative care research centre on research encounters with terminally ill patients in the home setting and to generate recommendations for qualitative researchers working in palliative and end-of-life care. The main areas that are discussed: 1) Whether participation in end-of-life research unintentionally becomes a therapeutic experience or an ethical concern; 2) Power relationships between terminally ill patients and researchers; 3) Researcher reflexivity and reciprocity; and, 4) Researchers' training needs. Qualitative methods can complement the home environment; however, it can raise ethical and practical challenges, which can be more acute in the case of research undertaken with palliative and patients at the end of life. The ... challenges researchers face in this context has the potential

to place both participant and researcher at risk for their physical and psychological well-being. <http://spcare.bmj.com/content/early/2015/12/08/bmjspcare-2015-000892.abstract>

First-year analysis of a new, home-based palliative care program offered jointly by a community hospital and local visiting nurse service

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 10 December 2015 – Patients were highly satisfied ... with their initial care and reported greater satisfaction ... and stable symptom management over time. Fewer emergency department ... and inpatient hospital admissions ... occurred among enrollees while on the palliative care service. <http://ajh.sagepub.com/content/early/2015/12/09/1049909115617139.abstract>

The critical care perspective in reply to 'Last rights: *Cuthbertson v. Rasouli* – What the supreme court didn't say about end-of-life treatment decisions'¹

HEALTH LAW IN CANADA, 2015;36(2):40-45. The ethical and legal challenges in end-of-life care are numerous, complex, and at the forefront of our understanding of who we are as individuals, how we are as a multicultural society, and the roles of medicine and law in framing our lives. Ultimately, the way in which any one of us deals with health issues and medical care depends on who we are and how we envision our self. In clinical practice, many people fear severe cognitive dysfunction more than severe physical disabilities. We identify who we are through our abilities to think, recognize and interact with those we love. Acknowledging this concept of our sense of self is often the basis for withholding or withdrawal of life-sustaining treatments, and even for consideration of organ donation after neurological or cardiac death. After the Supreme Court's ruling in *Carter*, it may also be a future consideration for requests for physician-assisted death. After all, it may not just be treatments that reach a point of only causing harm; sometimes the harm resides in living with severe intractable mental or physical illness, and how much a person is asked to endure.

1. 'Last rights: *Cuthbertson v. Rasouli* – What the supreme court didn't say about end-of-life treatment decisions,' *Health Law in Canada*, 2015;35(4):106-119. [Noted in Media Watch, 22 June 2015, #415 (pp.10-11)]

N.B. Access to *Health Law in Canada* requires a subscription to the newsletter. Publication's home page: <http://store.lexisnexis.ca/store/ca/catalog/booktemplate/productdetail.jsp?prodlid=prd-cad-00154>. Selected articles on the *Cuthbertson v. Rasouli* case noted in past issues of Media Watch are listed in the weekly report of 15 December 2014, #388 (pp.1-2).

Communication differences when patients and caregivers are seen separately or together

INTERNATIONAL JOURNAL OF PALLIATIVE NURSING, 2015;21(11):557-563. Southern Adelaide Palliative Care Services introduced a nurse-led early introduction to a palliative care clinic in 2011. The clinic offers a thorough psychosocial assessment and the provision of information and an introduction to future care planning. The patients and their caregivers are seen together by the nurse practitioner initially for a physical assessment. They are then seen by a social worker to focus on advanced care planning and assessment of social and emotional factors. After the social work visit, the patient and caregiver are separated, and the patient sees the psychosocial nurse for coping and adjustment to illness and the carer sees the caregiver network facilitator to assess their informal supports to assist in the role of community-based caregiving. An earlier evaluation of this clinic found that patients and their caregivers appreciate being separated in the clinic setting to have time and privacy to reveal fears and feelings related to end-of-life care. <http://www.magonlineibrary.com/doi/abs/10.12968/ijpn.2015.21.11.557>

How to get better care with lower costs? See the person, not the patient

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY | Online – 7 December 2015 – The U.S. health system perceives people as “patients” almost exclusively as they enter and exit the healthcare system, but with this emphasis on context, have we lost sight of the people who should be in the foreground of care? Does such a view impede care effectiveness and efficiency? How can we shift our frame of reference moving forward? To foster this conceptual shift, a group of thought-leaders convened by the American Geriatrics Society defined “person-centered care” to re-orient the perspective toward individuals remaining in the center of pursuing high-quality care. This article explores how a person-centered care approach can improve healthcare effectiveness and efficiency, particularly for older adults with heightened health and daily living needs, and healthcare costs. The process ... is outlined, three critical indicators that define person-centered quality are highlighted, and several models that embrace the person-centered paradigm are briefly noted. Although there is no one-size-fits-all schematic, how and why overall success entails fidelity to essential elements of person-centered programs as the Society expert panel identified is explained. <http://onlinelibrary.wiley.com/doi/10.1111/jgs.13867/abstract>

N.B. Additional articles on the concept of patient-centered care are listed on the journal’s “early view” page: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1532-5415/earlyview](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1532-5415/earlyview)

Related:

- *HEALTH AFFAIRS* | Online – 7 December 2015 – ‘**Primary care physicians in ten countries report challenges caring for patients with complex health needs.**’ A survey of primary care doctors in the U.S. and nine other countries reveals concern about how well prepared their practices are to manage the care of patients with complex needs and about their variable experiences in coordinating care and communicating with specialists, hospitals, home care, and social service providers. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/G9UWVHL9/Health%20Aff-2015-Osborn-2104-12.pdf>

Balancing hope and despair at the end of life: The contribution of organ and tissue donation

JOURNAL OF CRITICAL CARE | Online – 9 December 2015 – Concern for the grieving family can moderate the intentions of critical care staff to advocate deceased organ and tissue donation. Conversely, benevolent actions may provoke distress through missed opportunities to save or transform lives. This paper provides insight into the perceived benefits of organ and tissue donation for grieving families who experienced end-of-life care (EoLC) in the Intensive Care Unit (ICU). The study findings affirmed the importance of person-centred EoLC. Donor families shared examples of good quality care and communication that contained the hallmarks of compassion, respect, dignity and choice. Consent to donation appeared to give meaning to the life and death of the deceased person and was comforting to some families in their bereavement. [http://www.jccjournal.org/article/S0883-9441\(15\)00603-6/abstract](http://www.jccjournal.org/article/S0883-9441(15)00603-6/abstract)

N.B. Selected articles on organ donation in the context of end-of-life care noted in past issues of Media Watch are listed in the issue of the weekly report of 23 March 2015, #402 (p.2).

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

End-of-life care for undocumented immigrants with advanced cancer: Documenting the undocumented

JOURNAL OF PAIN & SYMPTOM MANAGEMENT | Online – 8 December 2015 – There are approximately 11.1 million undocumented immigrants in the U.S., with a majority being Latino. Cancer is now the leading cause of death in Latinos. There is little research guiding providers on how to deliver optimal end-of-life care in this population. The authors describe a case of an undocumented Latino patient with advanced cancer, and provide a review of the literature on end-of-life care in undocumented immigrants. Their patient encountered many challenges as he navigated through the healthcare system in the last months of life. These included delayed diagnosis, limited social support, financial issues, fear of deportation, and language and cultural barriers, which resulted in significant physical and psychological distress. Within the undocumented patient population, there is often a lack of advance care planning, prognostic understanding, mistrust, religious practices, and cultural beliefs that may affect decision making. Given the growing number of undocumented immigrants in the U.S., it is important for clinicians and policy makers to have a better understanding of the issues surrounding end-of-life care for undocumented immigrants, and work together to improve the quality of life and quality of end-of-life care for these disadvantaged individuals. [http://www.jpmsjournal.com/article/S0885-3924\(15\)00636-3/abstract](http://www.jpmsjournal.com/article/S0885-3924(15)00636-3/abstract)

Noted in Media Watch, 18 August 2014, #371 (p.13):

- *NARRATIVE INQUIRY IN BIOETHICS*, 2014;4(2)83-85. **'Undocumented and at the end of life.'** Three of the most contentious issues in contemporary American society – allocation of medical resources, end-of-life care, and immigration – converge when undocumented immigrant patients are facing the terminal phase of chronic illness. The lack of consistent, pragmatic policy in each of these spheres leaves us with little guidance for how to advocate for undocumented patients at the end of life. http://muse.jhu.edu/login?auth=0&type=summary&url=/journals/narrative_inquiry_in_bioethics/v004/4.2_mendola.html

Noted in Media Watch, 4 June 2012, #256 (p.12):

- *NEW ENGLAND JOURNAL OF MEDICINE* | Online – 31 May 2012 – **'Palliation for dying undocumented immigrants.'** At first glance, sending dying patients home at their request may appear to be an approach that would please advocates on both sides of the debate over illegal immigration. <http://www.nejm.org/doi/pdf/10.1056/NEJMp1201768>

Generalist palliative care in hospital – Cultural and organisational interactions

PALLIATIVE MEDICINE | Online – 7 December 2015 – It can be challenging to provide generalist palliative care (PC) in hospitals, owing to difficulties in integrating disease-oriented treatment with PC and the influences of cultural and organisational conditions. However, knowledge on the interactions that occur is sparse. [In this mixed-methods study, the authors investigated] the interactions between organisation and culture as conditions for integrated PC in hospital and, if possible, to suggest workable solutions for the provision of generalist PC. Two overall themes emerged: 1) Generalist PC as a priority at the hospital, suggesting contrasting issues regarding prioritisation of PC at different organisational levels; and, 2) Knowledge and use of generalist PC clinical guideline, suggesting that the guideline had not reached all levels of the organisation. Contrasting issues in the hospital's provision of generalist PC at different organisational levels seem to hamper the interactions between organisation and culture – interactions that appear to be necessary for the provision of integrated PC in the hospital. The implementation of PC is also hindered by the main focus being on disease-oriented treatment, which is reflected at all the organisational levels. <http://pmj.sagepub.com/content/early/2015/12/05/0269216315619861.abstract>

Cont.

Noted in Media Watch, 9 November 2015, #435 (p.16):

- *PALLIATIVE MEDICINE* | Online – 4 November 2015 – ‘**What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis.**’ Hospital-based specialist palliative care (SPC) services are common, yet existing evidence of inpatient generalist providers’ perceptions of collaborating with hospital-based SPC teams has never been systematically assessed. Five themes were identified as improving or decreasing effective collaboration... <http://pmj.sagepub.com/content/early/2015/11/04/0269216315615483.abstract>

Noted in Media Watch, 7 September 2015, #426 (p.16):

- *PALLIATIVE MEDICINE* | Online – 1 September 2015 – ‘**Palliative care in hospital: Why is it so difficult?**’ Care of the dying used to be the bread and butter of family doctors – why and where has that confidence gone? At the same time, families are not available or confident to care, community services are fragmented, we do not talk about dying, and we do not prepare or plan ahead. The end result ... is that thousands of people are admitted to hospital every day, and culture and systems make it very difficult to escape. <http://pmj.sagepub.com/content/early/2015/08/28/0269216315600996.full>

Please do whatever it takes to end our daughter’s suffering!

PEDIATRICS | Online – 7 December 2015 – What is the best way to care for a child with severe neurologic impairment who seems to be dying and is in intractable pain? Can we give sedation as we remove life support? Is it ethically permissible to hasten death? In the U.S. five states have legalized assisted suicide (though only for competent adults). In Belgium and The Netherlands euthanasia is legal for children under some circumstances. The authors present a case in which parents and doctors face difficult decisions about palliative care. Experts from Belgium, The Netherlands, and the U.S. then discuss how they would respond to such a case. http://pediatrics.aappublications.org/content/early/2015/12/07/peds.2015-3812?sso=1&sso_redirect_count=1&nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nfstatusdescription=ERROR%3a+No+local+token

Noted in Media Watch, 12 October 2015, #431 (p.14):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 October 2015 – ‘**Pediatrician ambiguity in understanding palliative sedation at the end of life.**’ Pediatricians [i.e., survey respondents] were concerned with a decreased level of consciousness as the goal of palliative sedation. Respondents were split on whether they view palliative sedation as a distinct entity or as one broad continuum of care, equivalent to aggressive symptom management. Institutional-based policies are essential to clarify acceptable practice, enable open communication, and promote further research. <http://ajh.sagepub.com/content/early/2015/10/05/1049909115609294.abstract>

Noted in Media Watch, 9 February 2015, #396 (p.11):

- *PEDIATRICS* | Online – 2 February 2015 – ‘**Are we allowed to discontinue medical treatment in this child?**’ One of the most difficult ethical dilemmas in pediatrics arises when a child has complex chronic conditions that are not curable and cause discomfort with no prospect of any improvement on quality of life. In the context of medical futility, it is harmful to prolong medical treatment. How can medical treatment be discontinued when the child is not dependent on mechanical ventilation or ICU treatment? What is the appropriate palliative care and does it justify the use of sedatives or analgesics if this also might shorten life? <http://pediatrics.aappublications.org/content/early/2015/01/28/peds.2014-0548.abstract>

[Media Watch: Palliative Care Network-e Website](http://www.pcn-e.com/community/pg/file/owner/MediaWatch)

The website promotes education amongst health care providers in places around the world where the know-ledge gap may be wider than the technology gap ... to foster education and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

The liminal and the parallax: Living and dying at the end of life

QUALITATIVE HEALTH RESEARCH | Online – 10 December 2015 – Transitions to palliative care (PC) can involve a shift in philosophy from life-prolonging to life-enhancing care. People living with a life-limiting illness will often receive PC through specialist outpatient clinics, while also being cared for by another medical specialty. Experiences of this point of care have been described as being liminal in character, that is, somewhere between living and dying. Drawing on experiences of illness and care taken from semi-structured interviews with 30 PC outpatients in Australia, the authors found that this phase was frequently understood as concurrently living and dying. They suggest that this is a “parallax experience” involving narratives of a coherent linear self that is able to understand both realities, in a way that acknowledges the benefits of being multiple. These findings have significant implications for the ways in which PC is understood and how the self and subjectivity might be conceptualized at the end of life. <http://qhr.sagepub.com/content/early/2015/12/09/1049732315618938.abstract>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN MEDICAL ASSOCIATION JOURNAL*, 2015;187(18):1339. ‘**Right to die in Canada: Respecting the wishes of physician conscientious objectors.**’ ...63% of Canadian physicians say they would refuse to provide medical aid in dying and so may find their convictions at odds with the law. The law is likely to give their patients the right to seek medical aid in dying, yet they as physicians would not wish to take part in that step. Clearly, doctors have no business denying patients their newly recognized right, no matter how strongly they may feel. But where does this leave physicians who, for whatever reason, do not wish to be involved with helping their patients to gain access to medical aid in dying? Those who would refuse, not only to offer medical aid in dying themselves, but also to refer a patient to another doctor for such a service, argue that referral would make them guilty by association of an act that they see as wrong. They have a point. <http://www.cmaj.ca/content/187/18/1339.full>
- *HEALTH LAW IN CANADA*, 2015;36(2):46-54. ‘**Physician-assisted death in Canada: As the law changes.**’ In *Carter v. Canada* (Attorney General) the Supreme Court of Canada (SCC) declared that the criminal law prohibition on physician assisted death will be unconstitutional, effective 7 February 2016. Quebec will be prepared with a statutory framework to govern the provision of physician-assisted death; Quebec’s Bill 52 was assented to on 10 June 2014 and will come into effect in December 2015. No other province has yet tabled legislation. Some may see these changes as a reflection of the evolution of palliative care and medical science within Canada and abroad. Others may view these changes as slap-dash experiment in physician assisted death. This article suggests that the truth is somewhere in between the two perspectives. Bill 52 reflects an attempt by Quebec legislators to regulate physician-assisted death. The SCC interpreted only the narrow point put to them, which was whether, in the cases before them, the blanket prohibition on physician-assisted death breached the Canadian Charter of Rights & Freedoms. The SCC did not establish a framework for physician-assisted death across Canada or comment on the Quebec legislation; however, both the legislation and the *Carter* decision raise questions about how physician-assisted death will be implemented in Canada. Rather than focusing on the arguments for and against physician-assisted death, this article focuses on Canada’s contribution to the global dialogue and considers some of the unanswered questions raised by *Carter* and Bill 52: questions about capacity, subjective suffering, and the potential for medical liability in the provision of physician-assisted death going forward. The authors suggest that these are the issues that will define the implementation of physician assisted death in Canada.

N.B. Access to *Health Law in Canada* requires a subscription to the newsletter. Publication’s home page: <http://store.lexisnexis.ca/store/ca/catalog/booktemplate/productdetail.jsp?prodId=prd-cad-00154>

- *JOURNAL OF MEDICINE & PHILOSOPHY* | Online – 8 December 2015 – ‘**First do no harm: Euthanasia of patients with dementia in Belgium.**’ This article explains the Belgian law and then explores arguments for and against euthanasia of patients with dementia. It probes the dementia paradox by elucidating Dworkin’s distinction between critical and experiential interests, arguing that at the end of life this distinction is not clear cut. It argues against euthanasia for patients with dementia, for respecting patients’ humanity and for providing them with more care, compassion, and good doctoring. <http://jmp.oxfordjournals.org/content/early/2015/12/08/jmp.jhv031.abstract>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/11/media-watch/>

INTERNATIONAL PALLIATIVE CARE RESOURCE CENTER: <http://www.ipcrc.net/archive-global-palliative-care-news.php>

PALLIATIVE CARE NETWORK COMMUNITY: <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

PALLIMED (Hospice & Palliative Medicine Blog): <http://www.pallimed.org/2013/01/the-best-free-hospice-and-palliative.html> [Scroll down to 'Aggregators' and Barry Ashpole and Media Watch]

Asia

ASIA PACIFIC HOSPICE PALLIATIVE CARE NETWORK: <http://aphn.org/category/media-watch/>

SINGAPORE | Centre for Biomedical Ethics (CENTRES): <http://centres.sg/updates/international-palliative-care-resource-center-media-watch/>

Australia

WESTERN AUSTRALIA | Palliative Care WA Inc: <http://palliativecarewa.asn.au/site/helpful-resources/> [Scroll down to 'International Websites' and www.ipcrc.net/archive-global-palliative-care-news.php to access the weekly report]

Europe

EUROPEAN ASSOCIATION FOR PALLIATIVE CARE: <http://www.eapcnet.eu/Themes/Organization/Links.aspx> [Scroll down to International Palliative Care Resource Center – IPCRC.NET]

HUNGARY | Hungarian Hospice Foundation: <http://hospicehaz.hu/alapitvanyunk/irodalom/nemzetkozi-kitekintes>

U.K. | Omega, the National Association for End-of-Life Care: <http://www.omega.uk.net/media-watch-hospice-palliative-care-and-end-of-life-news-n-470.htm?PHPSESSID=b623758904ba11300ff6522fd7fb9f0c>

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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Cont.

Something Missed or Overlooked?

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



Barry R. Ashpole

My involvement in hospice and palliative care dates from 1985. As a communications consultant, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My current work focuses primarily on advocacy and policy development in addressing issues specific to those living with a terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class college courses on different aspects of end-of-life care, and facilitating issue specific workshops, primarily for frontline care providers. Biosketch on the International Palliative Care Resource Center website at: <http://www.ipcrc.net/barry-r-ashpole.php>

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