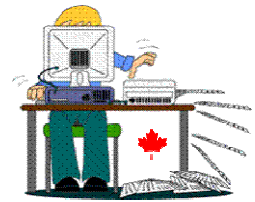


Media Watch...

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.

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Compiled & Annotated by Barry R. Ashpole

Terminology in end-of-life care: Scroll down to [Specialist Publications](#) and 'Clinician perspectives on challenges to patient centered care at the end of life' (p.12), in *Journal of Applied Gerontology*.

Canada

“Self-directed” home-care projects planned for Ontario following scathing report

ONTARIO | *The Globe & Mail* – 13 May 2015 – Ontario is moving to provide some home-care clients with pots of money they could spend as they choose on various in-home health services, a model known as “self-directed care,” that would be a first in Canadian home care. Health Minister Eric Hoskins announced ... that it will roll out pilot projects in self-directed care over the next two years, part of his government’s response to a scathing report on Ontario’s home and community care sector... Details on the self-directed care program were scant. No locations, dates or dollar figures have been set for the pilot projects... Ontario’s disjointed home-care system and the 14 local Community Care Access Centres (CCAC) that operate it have been under fire for years, mostly because of steep increases in executive compensation and accusations the organizations spend too much on administration and too little on front-line care. The heat is expected to be on the CCACs when the province’s Auditor-General reveals results of a special audit of their operations. <http://www.theglobeandmail.com/news/national/ontario-health-minister-expected-to-address-scathing-report-on-home-care/article24415170/>

Community Care Access Centres may be on way out

ONTARIO | *The London Free Press* – 14 May 2015 – Health Minister Eric Hoskins may be weeks away from changes that would take power and money away from 14 large bureaucracies that act as gatekeepers to home care... Hoskins said he wanted to make changes but would wait until Auditor General Bonnie Lysyk releases her report...<http://www.lfpress.com/2015/05/14/ccacs-may-be-on-way-out>

Compassionate leave benefits increased

NOVA SCOTIA | *The Chronicle Herald* (Halifax) – 13 May 2015 – People caring for a severely ill family member will be eligible for greater financial support starting next year through the federal employment insurance program. The new program will allow claimants to collect up to 26 weeks of benefits, up from the current six weeks. <http://thechronicleherald.ca/novascotia/1286551-compassionate-leave-benefits-increased>

Cont.

Noted in Media Watch, 16 March 2015, #401 (p.1):

- ONTARIO | *The Toronto Star* – 12 March 2015 – ‘**Ontario’s home care system should be overhauled now: Editorial.**’ A study by the Ontario Health Coalition, an advocacy group, is calling for a complete overhaul of the home care system.¹ If their message isn’t strong enough to be heard by the Ontario government, many of the group’s findings are reinforced by a second report on home care by a group of experts commissioned by the provincial government.²
<http://www.thestar.com/opinion/editorials/2015/03/12/ontarios-home-care-system-should-be-overhauled-now-editorial.html>
 1. ‘The Care We Need: Ontarians Speak Out on the State of Home Care – A Proposal for Reforming Home Care in the Public Interest,’ Ontario Health Coalition, March 2015.
<http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf>
 2. ‘Bringing Care Home,’ Report of the Expert Group on Home & Community Care,’ March 2015.
http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

Study finds 18% of north-eastern Ontario cancer patients die before seeing specialist

ONTARIO | CBC News – 12 May 2015 – A new study reveals some cancer patients die in north-eastern Ontario without ever meeting with a medical specialist.¹ Researchers examined 6,500 cancer patients in the Sudbury-Manitoulin area over five years. They found just over 18% never met with an oncologist or got palliative care. Patients who were older or who lived in a rural area were significantly less likely to have had a consultation, the study found. “We do know that in terms of palliative care there’s a lot of opportunity and need for improvement,” said Mark Hartman, one of the researchers and the regional vice-president with the North East Regional Cancer Program. “So that’s really what the focus of this study was about, how we could improve access to palliative care services.” The results are probably consistent across the province, he added.
<http://www.cbc.ca/news/canada/sudbury/study-finds-18-of-northeastern-ontario-cancer-patients-die-before-seeing-specialist-1.3069542>

1. ‘Access to oncology consultation in a cancer cohort in northeastern Ontario,’ *Current Oncology*, 2015;22(2):e69-375. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4399626/>

Do the dying have the right to experimental drugs?

THE GLOBE & MAIL | Online – 11 May 2015 – Should terminally ill patients have the right to try experimental treatments? The emotional, knee-jerk response most of us have to that question is: “Of course, what have they got to lose?” But who should be able to access drugs, and when, is actually one of the thorniest ethical issues and hottest political issues in health care today. In the past year, 17 U.S. states have passed “right-to-try” laws, with little political opposition and even less critical examination. These laws, championed by the libertarian Goldwater Institute, are based on the premise that “terminal patients shouldn’t have to ask the government for permission to save their own lives,” in the words of the group’s

president, Darcy Olsen. The assumption here is that only the patient has anything to lose (or gain). That’s not true. Neither is the argument that the paperwork for gaining access to experimental drugs now is too onerous. <http://www.theglobeandmail.com/globe-debate/do-the-dying-have-the-right-to-experimental-drugs/article24377706/>

Extract from *The Globe & Mail* article

People who are terminally ill deserve compassion, but in our bid to be compassionate, we should not be offering up false hope, nor undermining the benefits to others.

Cont.

Selected articles on “right-to-try” laws in the U.S. noted in past issues of Media Watch:

- U.S. | *The New York Times* – 10 January 2015 – **‘Patients seek “right to try” new drugs.’** Since May, a string of states have passed laws that give critically ill patients the right to try medications that have not been approved by the Food & Drug Administration. Critics of the laws ... call them “a cruel sham.” [Noted in Media Watch, 19 January 2015, #393 (p.2)] http://www.nytimes.com/2015/01/11/us/patients-seek-right-to-try-new-drugs.html?ref=health&_r=0
- *CLINICAL TRIALS*, 2014;11(5):519-520. **“Right to try” laws.** A federal bill was developed a decade ago – ‘Access, Compassion, Care & Ethics for Seriously Ill Patients Act.’ At the time, the Society for Clinical Trials prepared a position paper opposing this legislation. [Noted in Media Watch, 27 October 2014, #381 (p.6)] <http://ctj.sagepub.com/content/11/5/519.full>
- *JAMA INTERNAL MEDICINE* | Online – 29 September 2014 – **‘The strange allure of state “right-to-try” laws.’** Laws that purport to allow patients to be treated with unapproved drugs ... seem likely to be futile. [Noted in Media Watch, 6 October 2014, #378 (p.11)] <http://archinte.jamanetwork.com/article.aspx?articleid=1910562>

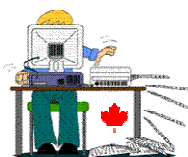
Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 14 May 2015 – **‘With too few Canadians having access to palliative care, little wonder we’re afraid of dying.’** Those of us working in healthcare understand that life-altering illness, trauma or anticipation of death can sometimes sap will to live. In those instances, health-care providers are called upon to commit time; time to manage distress, provide unwavering support and to assuage fear that patients might be abandoned to their hopelessness and despair. That is the essence of how medicine has traditionally responded to suffering. Stopping time by way of arranging the patient’s death has never been part of that response. <http://news.nationalpost.com/full-comment/harvey-chochinov-with-too-few-canadians-having-access-to-palliative-care-little-wonder-were-afraid-of-dying>
- iPOLITICS | Online – 11 May 2015 – **‘Federal government has already begun consultations on physician assisted death: MacKay.’** Stephen Harper’s government has quietly begun consultations on the emotionally charged issue of doctor-assisted suicide even though there has not yet been a public call for comments, Justice Minister Peter MacKay revealed. “The consultation, while not formally announced, has begun and we have already, without soliciting, received input on the subject matter.” <http://www.ipolitics.ca/2015/05/11/federal-government-has-already-begun-consultations-on-physician-assisted-death-mackay/>

Noted in Media Watch, 16 February 2015, #397 (p.3):

- *THE TORONTO STAR* | Online – 10 February 2015 – **‘Feds will not override the court’s ban on assisted suicide, MacKay hints.’** After the Supreme Court struck down Canada’s ban on doctor-assisted suicide, the justice minister says there are no plans to override that ruling. Peter MacKay said the Conservatives will solicit a range of views on doctor-assisted suicide, including from the medical profession and those living with disabilities. <http://www.thestar.com/news/queenspark/2015/02/10/feds-will-not-override-the-courts-ban-on-assisted-suicide-mackay-hints.html>



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>

[U.S.A.](#)

Dying without dignity: A growing trend

TENNESSEE | WDEF News (Chattanooga) – 14 May 2015 – Professional hospice care is meant to give terminally ill people an opportunity to die in comfort with as much dignity as possible. But there's a growing trend of terminally ill people who have a tough time gaining access to hospice care because of their social-economic status. Medicare covers hospice 100%. But that coverage is limited by time so patient must only have six months or less to live. Also, Medicare does not cover assisted living. This is when end-of-life care becomes an out-of-pocket expense. <http://www.wdef.com/news/story/Dying-without-dignity-a-growing-trend/WWrMk20aoUGwb0ECgtel-g.csp>

A top-rated nursing home is hard to find in Texas, 10 other states

TEXAS | *Kaiser Health News* – 14 May 2015 – Texas has the highest percentage of one-and two-star homes in the country: 51% of its nursing homes are rated “below average,” or “much below average,” on Nursing Home Compare, according to the analysis. Louisiana is close behind at 49%, with Oklahoma, Georgia and West Virginia tying for third at 46%. Other states with at least 40% of homes ranked at the bottom two rungs include North Carolina, Tennessee, Kentucky, Ohio, Pennsylvania and New York. Earlier this year, the government added quality criteria and as a result, many nursing homes dropped a star or more. In 11 states, 40% or more of nursing homes get the two lowest ratings, according to an analysis by the Kaiser Family Foundation.¹ <http://kaiserhealthnews.org/news/a-top-rated-nursing-home-is-hard-to-find-in-texas-10-other-states/>

1. 'Reading the Stars: Nursing Home Quality Star Ratings, Nationally and by State,' Kaiser Family Foundation, May 2015. <http://files.kff.org/attachment/issue-brief-reading-the-stars-nursing-home-quality-star-ratings-nationally-and-by-state>

Noted in Media Watch, 30 March 2015, #403 (p.6):

- *NEW YORK MAGAZINE* | Online – 24 March 2015 – ‘**Many nursing homes fall short at palliative care.**’ How good are American nursing homes at palliative care? Given that these are the settings in which many people spend the last days of their lives, it's an important question. Prior research has shown that in the absence of solid end-of-life planning, many people who are close to death endure painful, intrusive medical procedures that add little to their lives' quality or quantity and that may in some cases actually detract from both. Somewhat alarmingly, 21% of the directors of nursing [recently] surveyed “correctly responded to none or only one of the knowledge items, and 43% to all items.”¹ More than half ... didn't appear to know the basics of how palliative care works. <http://nymag.com/scienceofus/2015/03/many-nursing-homes-fall-short-at-palliative-care.html>

1. 'End-of-life care in nursing homes with greater versus less palliative care knowledge and practice,' *Journal of Palliative Medicine*, 16 March 2015. This study included 1,981 nursing homes with complete survey responses and the 58,876 residents who died in these facilities between 2009-2010. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0393?journalCode=jpm>

N.B. Several articles on the quality of end-of-life care in nursing homes noted in past issues of Media Watch are listed in the issue of the weekly reported of 15 December 2014, #388 (pp.12-13).

[Media Watch Online](#)

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.15.

As CARE Act takes effect, study shows caregivers want – and need – more information

NEW JERSEY | *New Jersey Biz* – 13 May 2015 – This week the CARE Act goes into effect, requiring that a hospital patient's designated caregiver ... receives instruction on how to provide at-home care before the patient goes home. And a new report¹ ... finds that caregivers are looking for more help carrying out their essential role – one that's expected to become more widespread as society moves toward providing more care at home and in the community, rather than in nursing homes and other facilities. <http://www.njbiz.com/article/20150513/NJBIZ01/150519916/as-care-act-takes-effect-study-shows-caregivers-want--and-need--more-information>

1. 'Supporting Family Caregivers in New Jersey,' Rutgers Center for State Health Policy, May 2015. <http://www.cshp.rutgers.edu/Downloads/10700.pdf>

Going back to work while grieving

THE WASHINGTON POST | Online – 13 May 2015 – It turns out that about 85% of companies offer bereavement leave as a benefit, according to the Society for Human Resource Management and ... that the typical policy is 3-5 days. The exact number frequently depends on whether the death is in the immediate or extended family. There have been efforts at the federal and state level to mandate some kind of minimum floor, however, at least for unpaid bereavement leave. A bill co-sponsored by eight Democratic senators and a companion bipartisan bill in the House were introduced that would amend the federal Family & Medical Leave Act to include parents who are grieving the death of a child. The Act already provides unpaid leave and pro-

pects employees' jobs for 12 weeks under certain conditions, such as childbirth or caring for family members with serious health issues. It doesn't cover bereavement. <http://www.washingtonpost.com/blogs/on-leadership/wp/2015/05/13/going-back-to-work-after-a-death-in-the-family/>

Specialist Publications

'Death and the workplace' (p.11), in *Illness, Crisis & Loss*.

'Experiencing loss: A Muslim widow's bereavement narrative' (p.12), in *Journal of Religion & Health*.

Noted in Media Watch, 22 December 2014, #389 (p.16):

- *BEREAVEMENT CARE*, 2014;33(3):111-112. 'Handling bereavement in the workplace – a guide for [U.K.] employers.' The authors discuss the recently published Advisory, Conciliation & Arbitration Service guidance for employers on handling bereavement in the workplace.¹ <http://www.tandfonline.com/doi/full/10.1080/02682621.2014.980986>
 1. 'Managing bereavement in the workplace: A good practice guide,' Advisory, Conciliation & Arbitration Service, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.15)] <http://www.acas.org.uk/media/pdf/0/m/Managing-bereavement-in-the-workplace-a-good-practice-guide.pdf>

Noted in Media Watch, 6 October 2014, #378 (p.15):

- *WORK: A JOURNAL OF PREVENTION, ASSESSMENT & REHABILITATION* | Online – 23 September 2014 – 'Excluding parental grief: A critical discourse analysis of bereavement accommodation in Canadian labour standards.' Universally, employment policies provide only for the practical issues of bereavement. They do not acknowledge the long-term suffering caused by grief or the variable intensity of different kinds of loss. Managerial, moral, normative and neoliberal values embedded in these policies efface the intensely personal experience of grief, thereby leaving employees at risk for serious health and workplace safety issues. <http://iospress.metapress.com/content/y846mju257307701/>

What do cancer centers think patients are looking for?

FORBES | Online – 11 May 2015 – If you were a cancer center trying to get patients to come to receive care at your facility, what message would you send them? In other words, what would you as a cancer center director think people would value in choosing a place to receive cancer care? One way to answer this would be to survey cancer center directors. You could conduct face-to-face interviews or written surveys. You could hold focus groups, if you could get all the directors in a room together. But Laura Vater and colleagues from the University of Pittsburgh had a much cleverer and simpler way to answer this question.¹ They analyzed cancer center advertisements ... from U.S. consumer magazines and television networks, dutifully analyzed the topics covered in each ad, and tabulated the results. What they found is telling, if not totally surprising. For starters, they found that advertisements frequently target people's desire for hope, for miracles, and for a healthcare team that will fight against all odds. Less often, the ads tout quality of life issues and, even more rarely, emphasize the part of medical care which deserves a much larger role in cancer treatment – shared decision-making. Only 2% of cancer center advertisements mention palliative care. <http://www.forbes.com/sites/peterubel/2015/05/11/what-do-cancer-centers-think-patients-are-looking-for/>

1. 'What are cancer centers advertising to the public?: A content analysis of cancer center advertisements,' *Annals of Internal Medicine*, 2014;160(12):813-820. [Noted in Media Watch, 9 June 2014, #361 (p.13)] <http://annals.org/article.aspx?articleid=1874737>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NEW YORK TIMES* | Online – 13 May 2015 – 'When doctors help a patient die.' Medical aid in dying is now allowed in Oregon, Washington and Vermont by legislation and in Montana and New Mexico through court decisions. The laws provide direction and protection for those involved. In Oregon, Washington and Vermont, when terminally ill patients request physician assistance in dying, it is not considered suicide, and the death certificate notes the underlying illness as the cause of death. http://opinionator.blogs.nytimes.com/2015/05/13/the-ethics-for-doctors-in-helping-a-patient-die/?_r=0

International

End-of-life care in Northern Ireland

More support for cancer patients needed – report

U.K. (Northern Ireland) | UTV Ireland News (Dublin) – 15 May 2015 – Almost three quarters of cancer patients who died in Northern Ireland in a six-month period wished to do so at home, but only a third of patients did. Researchers heard from 467 relatives and carers of cancer patients in Northern Ireland who died between December 2011 to May 2012.¹ While almost three quarters (74.7%) expressed a preference to die at home, only over a third (38.2%) of patients actually died at home, 41.1% in hospital, 12.0% in a hospice and 8.8% in a care home. The report ... has identified key factors influencing what enables cancer patients to die at home if that is their preference. It recommends the need to address these key factors urgently as the number of cases of cancer, which has increased 40% over the past 20 years, is now set to increase by a further 66% over the next 20 years. Factors linked with achieving a home death include: good communication about end of life care; having a key health care worker linking with the patient and family and relatives and carers providing help in the home. <http://www.u.tv/News/2015/05/15/More-support-for-cancer-patients-needed---report-37280>

Cont.

1. 'Dying with Cancer: Perspectives of Bereaved Relatives/Friends,' Northern Ireland Cancer Registry, Queen's University, Belfast, 2015. <http://www.cancerfocusni.org/wp-content/uploads/FINAL-QUALYCARE-REPORT-01-04-2015-with-Foreward-24.04.2015-NEW.compressed.pdf>

Noted In Media Watch, 9 March 2015, #400 (p.5):

- U.K. (Northern Ireland) | *The Belfast Telegraph* – 3 March 2015 – '**New poll reveals concerns over cancer treatment in Northern Ireland.**' Seven out of 10 people in Northern Ireland have concerns over how the pain of a terminally ill loved one would be managed during cancer treatment. A Marie Curie poll showed 45% of Northern Ireland respondents would also be worry that a loved one would not have access to round-the-clock care and support if diagnosed with a terminal illness <http://www.belfasttelegraph.co.uk/news/northern-ireland/new-poll-reveals-concerns-over-cancer-treatment-in-northern-ireland-31035292.html>

1. 'Marie Curie: U.K. Public Opinion on Taking Care of a Loved One with a Terminal Illness,' ComRes, 2 March 2015. <http://comres.co.uk/wp-content/uploads/2015/02/Marie-Curie - Terminal-Illness-Survey.pdf>

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

End-of-life care should be a priority for the new Conservative government

U.K. (England, Northern Ireland, Scotland & Wales) | Carehome.co.uk – 14 May 2015 – Nearly two-thirds of people in Britain would like to see end-of-life care being made a priority by the new Tory Government, according to a new study. The ComRes research commissioned by the Dying Matters Coalition, also found that three-quarters of people (75%) agree that providing end-of-life care should be a fundamental part of the work of the National Health Service. A huge part of the problem is that discussing dying and making end of life plans remains a taboo for millions of people in the U.K. The Dying Matters Coalition found that although a third of British adults (32%) think about dying and death at least once a week, 72% of the public believe that people in Britain are uncomfortable discussing dying, death and bereavement. Only 35% of the public say they have written a will, 32% that they have registered as an organ donor or have a donor card, 31% that they have taken out life insurance and 27% that they have talked to someone about their funeral wishes. <http://www.carehome.co.uk/news/article.cfm/id/1568984/end-of-life-care-priority-conservative-government>

Specialist Publications

'Choice and compassion at the end of life: A critical analysis of recent English policy discourse' (p.13), in *Social Science & Medicine*.

Children's hospices need ringfenced cash

U.K. | *The Guardian* – 14 May 2015 – Short breaks for families caring for a child who may not reach adulthood mean more than just a holiday – they provide vital respite and help families to cope with the pressure of providing round-the-clock care for their children. They rely on frequent short breaks with specialist care, provided by a range of organisations including children's hospices, to enable them to spend time as a family – recharging batteries, making memories with the seriously ill child and spending quality time with brothers and sisters. However, too few local authorities fund these crucial services for children with complex conditions, meaning families struggle and will often need more expensive emergency support from health or social care. <http://www.theguardian.com/society/2015/may/14/children-hospices-ringfenced-cash>

Doctors urged to stop “over-treating”

U.K. | BBC News – 13 May 2015 – Doctors’ leaders have launched a major campaign to stop medics “over-treating” their patients in ways that do not help and could even harm them. Writing in the *British Medical Journal*, they suggest some patients are given pills or have tests they do not need by doctors who feel under pressure to act.¹ They argue patients should feel able to discuss whether there are simpler, safer options that are right for them. But experts warn they must not change treatment without medical advice. The Academy of Medical Royal Colleges says there is growing evidence that pressure for doctors to “do something” at each consultation has led to patients sometimes receiving treatments that are of little or no value. And the report suggests a culture of “more is better” means some individuals are being over-diagnosed – labelled with conditions that may in the end do them little harm. <http://m.bbc.com/news/health-32703632>

1. ‘Choosing Wisely in the U.K.: the Academy of Medical Royal Colleges’ initiative to reduce the harms of too much medicine,’ *British Medical Journal*, 12 May 2015. The authors explain how and why a U.S. initiative to get doctors to stop using interventions with no benefit is being brought to the U.K. <http://www.bmj.com/content/350/bmj.h2308>

Noted in Media Watch, 2 March 2015, #399 (p.8):

- *JAMA INTERNAL MEDICINE* | Online – 25 February 2015 – ‘**Challenges in Choosing Wisely’s international future.**’ The American Board of Internal Medicine Foundation’s ‘Choosing Wisely’ campaign has affected sixty U.S. specialty societies and is becoming an international phenomenon. <http://archinte.jamanetwork.com/article.aspx?articleid=2130720>

Noted in Media Watch, 7 July 2014, #365 (p.8):

- *HEMONC TODAY* | Online – 30 June 2014 – ‘**Hospice/palliative care association outlines five things physicians should question.**’ When it comes to the avoidance of unnecessary tests, procedures or treatments, there is arguably no setting in which it is more important to “choose wisely” than end-of-life care. <http://www.healio.com/hematology-oncology/palliative-care/news/online/%7Bcc1dd49f-a523-42d5-898b-092025767ffb%7D/hospicepalliative-care-association-outlines-5-things-physicians-should-question>

[Back Issues of Media Watch](#)



The screenshot shows the IPCRC.NET website. The header includes the logo and navigation links: Home, About IPM, OIA, NCI, Partners, Contact, Acknowledgements. The main content area features the text: 'GLOBAL PALLIATIVE CARE NEWS ARCHIVE', 'MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE', and a list of 'Media Watch Archives' with links for various periods from 2011 to 2014. A preview of a news item is also visible.

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>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- AUSTRALIA | *The Age* – 13 May 2015 – ‘**Disobedience: A path to clarity in end-of-life law.**’ It is a self-evident truth that dying can be accompanied by intolerable and unrelievable suffering which may escalate as death approaches. It is also self-evident that some suffering will end only with death. Doctors have an ethical duty to relieve suffering, and to respect the autonomy of their patients. The Medical Treatment Act says it is desirable that dying patients receive maximum relief of pain and suffering. So what does a doctor do when a person with intolerable and unrelievable suffering asks for assistance to die to relieve that suffering? <http://www.theage.com.au/comment/disobedience-a-path-to-clarity-in-endoflife-law-20150513-ggzqtl.html>

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

Language barriers to defining concepts in medicine: The case of palliative sedation

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE | Online – 13 May 2015 – Defining a concept is the process of describing its measurable properties and specifying the units of analysis to which the concept applies. Based on the classical concept theory, all concepts have a definitional structure formed by a list of features that must comprise two essential attributes, that is, necessity and sufficiency. The former entails that all denoted members share each of the features described, whereas the latter that each feature contains all parts required for a clear and unambiguous definition. Should one of these attributes is not fully satisfied, a definition can be challenged as inadequate, inappropriate, or problematic. Palliative sedation, a medical concept for which numerous attempts at a definition have been recorded over time, can be used as a case in point. <http://ajh.sagepub.com/content/early/2015/05/12/1049909115586186.extract>

Noted in Media Watch, 12 May 2014, #357 (p.6):

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: An analysis of international guidelines and position statements.**’ Guidelines were published by American College of Physicians-American Society of Internal Medicine (2000), Hospice & Palliative Nurses Association (2003), American Academy of Hospice & Palliative Medicine (2006), American Medical Association (2008), Royal Dutch Medical Association (2009), European Association for Palliative Care (2009), National Hospice & Palliative Care Organization (2010), and National Comprehensive Cancer Network (2012). <http://ajh.sagepub.com/content/early/2014/05/06/1049909114533002.abstract>

Incorporating spirituality into patient care

AMERICAN MEDICAL ASSOCIATION JOURNAL OF ETHICS, 2015;17(5):409-415. There is an increasing recognition in modern Western medicine of the importance of patient spirituality in treatment and healing. Nowhere is this more important than in addressing and resolving dilemmas in bedside medical ethics. It is thus important for clinicians to know how to take, and to be comfortable with taking, a patient’s spiritual history in a nonintrusive way. Health care professionals must likewise recognize when their own values raise dilemmas in their practice of medicine and must be able to deal with issues that may arise from their own right of conscience. <http://journalofethics.ama-assn.org/2015/05/spec1-1505.html>

Cont.

Selected articles on spirituality, in the context of end-of-life care, noted in past issues of Media Watch:

- *WESTERN JOURNAL OF NURSING RESEARCH* | Online – 25 May 2014 – ‘**Describing spirituality at the end of life.**’ The authors’ analysis of the literature identified five attributes that most commonly described the essence of spirituality: 1) meaning; 2) beliefs; 3) connecting 4) self-transcendence; and, 5) value. [Noted in Media Watch, 2 June 2014, #360 (p.12)] <http://wjn.sagepub.com/content/early/2014/05/23/0193945914535509.abstract>
- *JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2013;9(2-3). ‘**Spirituality in end-of-life and palliative care: Theory, research, and practice dimensions for social work.**’ The theme of this issue of the journal is “theoretical and practice perspectives in which spirituality plays a key role in end-of-life care.” [Noted in Media Watch, 24 June 2013, #311 (p.12)] Contents page: <http://www.tandfonline.com/toc/wswe20/current>
- *ARCHIVE FOR THE PSYCHOLOGY OF RELIGION*, 2012;34(1):63-81. ‘**Six understandings of the word “spirituality” in a secular country.**’ The authors conclude that a common understanding of the term spirituality does not exist, at least in a modern secular setting. [Findings of this Danish study] resulted in [identifying] six different understandings of spirituality: 1) positive dimensions in human life and well-being; 2) New Age ideology; 3) an integrated part of established religious life; 4) a vague striving, opposed to religion; 5) selfishness; and, 6) ordinary inspiration in human activities. [Noted in Media Watch, 25 June 2012, #259 (p.9)] <http://www.ingentaconnect.com/content/brill/arp/2012/00000034/00000001/art00005>

Evidence of what works to support and sustain care at home for people with dementia: A literature review with a systematic approach

BMC GERIATRICS | Online – 13 May 2015 – In many areas, policy and practice developments are proceeding on a limited evidence base. Key issues affecting substantial numbers of existing studies include: 1) poorly designed and overly narrowly focused studies; 2) variability and uncertainty in outcome measurement; 3) lack of focus on the perspectives of people with dementia and supporters; and, 4) failure to understanding the complexities of living with dementia, and of the kinds of multifactorial interventions needed to provide holistic and effective support. <http://www.biomedcentral.com/content/pdf/s12877-015-0053-9.pdf>

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

- *INTERNATIONAL PSYCHOGERIATRICS* | Online – 13 February 2015 – ‘**An evaluation of palliative care contents in national dementia strategies in reference to the European Association for Palliative Care white paper.**’ Although palliative care was not explicitly referred to in 8 of the 14 countries reviewed, and only to a limited extent in 3 countries, a number of domains from the Association’s white paper were well represented, including “person-centered care, communication, and shared decision making”; “continuity of care”; and “family care and involvement.”¹ Three countries that referred to palliative care did so explicitly... <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9557793&fulltextType=RA&fileId=S1041610215000150>
 1. ‘White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care,’ *Palliative Medicine*, published online 4 July 2013. [Noted in Media Watch, 8 July 2013, #313 (p.8)] <http://pmj.sagepub.com/content/early/2013/07/03/0269216313493685.abstract>
- *BMC GERIATRICS* | Online – 6 February 2015 – ‘**What should we know about dementia in the 21st Century? A Delphi consensus study.**’ This study identified information about dementia that experts consider essential for a contemporary understanding of the condition. While expert consensus supports a diverse range of domains as critical in understanding dementia, information about the provision of care was prominent. The findings may assist clinicians and academics to convey information about dementia to colleagues, health workers, and the general public, as well as facilitate the development of education and knowledge-evaluation products. <http://www.biomedcentral.com/content/pdf/s12877-015-0008-1.pdf>

Male-female patient differences in the association between end-of-life discussions and receipt of intensive care near death

CANCER | Online – 14 May 2015 – Patient gender plays a significant role in patient-physician communication, patients' understanding of illness, and the aggressiveness of end-of-life (EoL) care. However, little is known about the extent to which gender differences in the effects of EoL discussions on EoL care contribute to gender differences in EoL care. This study was aimed at determining whether gender differences existed in the receipt of intensive care unit (ICU) care near death and in the association between EoL discussions and the receipt of EoL ICU care. Men with advanced cancers are more likely than women [i.e., the participants in this study] to receive aggressive, non-beneficial ICU care near death. Gender differences in the effects of EoL discussions on EoL care likely contribute to and may even explain gender differences in the receipt of ICU care in the last week of life. <http://onlinelibrary.wiley.com/doi/10.1002/cncr.29417/abstract>

Death and the workplace

ILLNESS, CRISIS & LOSS | Online – 13 May 2015 – It is well known that bereavement presents major challenges of adjustment to the individuals so affected, but what is much less well recognized is the major challenges bereavement can present to organizations in general and their managers and human resources professionals in particular. This article explores the significance of death for the workplace and argues that organizations that fail to give adequate attention to such matters will be poorly placed when it comes to promoting workplace well-being. <http://icj.sagepub.com/content/early/2015/05/13/1054137315585445.abstract>

What is palliative care?

INNOVAIT | Online – 12 May 2015 – This article aims to explore the different points at which palliative care may begin and summarise new guidance that may inform management. Palliative care is a core part of the role of a GP. It can and should begin as early as possible in a patient's course of illness, but as GPs we may individually become involved at a variety of points without necessarily having had the opportunity to build a prior relationship with a patient. This can be challenging, particularly if seeing a patient for the first time when they are in the last days of life. <http://ino.sagepub.com/content/early/2015/05/11/1755738015581025.abstract>

Of related interest:

- *NEURO-ONCOLOGY PRACTICE* | Online – 12 May 2015 – '**Essential competencies in palliative medicine for neuro-oncologists.**' The authors identify some of the barriers to incorporation of palliative care in standard neuro-oncology practice and equate competency in neuro-oncology with competency in the basic tenets of palliative medicine. <http://nop.oxfordjournals.org/content/early/2015/05/11/nop.npv011.abstract>
- *SEMINARS IN PEDIATRIC NEUROLOGY* | Online – 12 May 2015 – '**A parent's journey: Incorporating principles of palliative care into practice for children with chronic neurological diseases.**' Pediatric neurologists, as sub-specialists who provide medical care for children with chronic and complex conditions, should consider invoking the principles of palliative care early in the course of a disease process, either through applying general facets or, if available, through consultation with a specialty palliative care service. [http://www.sempedneurjn.com/article/S1071-9091\(15\)00043-1/abstract](http://www.sempedneurjn.com/article/S1071-9091(15)00043-1/abstract)

[Media Watch posted on Palliative Care Network-e Website](#)

Palliative Care Network-e (PCN-e) promotes education amongst health care providers in places around the world where the knowledge gap may be wider than the technology gap ... to foster teaching and interaction, and the exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>

Terminology in end-of-life care

Clinician perspectives on challenges to patient centered care at the end of life

JOURNAL OF APPLIED GERONTOLOGY | Online – 8 May 2015 – To better understand barriers to the expression and realization of patients' end-of-life wishes, a preventive ethics team in one [U.S.] Veterans Affairs Medical Center conducted a survey of physicians, nurses, social workers, and respiratory therapists. Analysis revealed barriers to patient wishes being identified and followed, including – 1) discomfort conducting end-of-life discussions; 2) difficulty locating patients' preferences in medical records; 3) challenges with expiring do not resuscitate (DNR) orders; 4) and confusion over terminology. Based on these findings, the preventive ethics team proposed new terminology for code status preferences, elimination of the local policy for expiration of DNR orders, and enhanced systems for storing and retrieving patients' end-of-life preferences. <http://jag.sagepub.com/content/early/2015/05/07/0733464815584668.abstract>

Selected articles on terminology *vis-à-vis* resuscitation noted in recent issues of Media Watch:

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 31 March 2015 – **“Allow Natural Death” versus “Do Not Resuscitate”: What do patients with advanced cancer choose?** All 93 of the participants who completed a survey were considered by their attending physician to have a terminal illness, but only 42% of these interviewees believed they were terminally ill. In addition, only 25% of participants thought that their primary oncologist knew their end-of-life wishes. Participants were equally likely to choose either of the “no code” options in all hypothetical scenarios... A similar proportion of patients who had a living will chose AND and DNR orders instead of “full code” in all the scenarios. In contrast, among patients who did not have a living will, 52% chose DNR, while 19% opted for AND. [Noted in Media Watch, 6 April 2015, #404 (p.9)] <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0369>
- *BMJ OPEN* | Online – 13 January 2015 – **‘Variation in local trust Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) policies: A review of 48 English healthcare trusts.’** There was variation in terminology (85% described documents as policies, 6% procedures, and 8% guidelines). Only one quarter of Trusts used the recommended Resuscitation Council (U.K.) record form (or a modification of the form). There was variation in the terminology used, which included DNAR (do not attempt resuscitation), DNACPR, CPR and AND (allow natural death). Selected articles on spirituality, in the context of end-of-life care, noted in past issues of Media Watch: <http://bmjopen.bmj.com/content/5/1/e006517.full>

Experiencing loss: A Muslim widow’s bereavement narrative

JOURNAL OF RELIGION & HEALTH | Online – 10 May 2015 – The authors explore how Islam, minority status and refugee experiences intersect in shaping meaning-making processes following bereavement. We do this through a phenomenological analysis of a biographical account of personal loss told by Aisha, a Muslim Palestinian refugee living in Denmark, who narrates her experience of losing her husband to lung cancer. By drawing on a religious framework, Aisha creates meaning from her loss, which enables her to incorporate this loss into her life history and sustain agency. Her narrative invites wider audiences to witness her tale of overcoming loss, thus highlighting the complex way in which religious beliefs, minority status and migration history come together in shaping meaning-making processes, and the importance of reciprocity in narrative studies. <http://link.springer.com/article/10.1007/s10943-015-0058-x>

Organ donation, ethnicity and the negotiation of death: Ethnographic insights from the U.K.

MORTALITY | Online – 6 May 2015 – The introduction of end-of-life care criteria in the U.K. aims at standardising the processes of care at the end of life, including how medical decisions on death are communicated to the families of dying and (brain) dead patients. In the setting of the intensive care unit, these activities are routinely complicated by the imperative to secure donor organs for transplantation: where recent changes to donation services have seen the accommodation of organ donation procedures into end-of-life care routines. This has ramifications for understanding how medical decisions around death and dying are brokered with the families of potential organ donors. This paper documents how communications around death get turned into a particular matter of concern for the practice of requesting organ donation from minority ethnic families. <http://www.tandfonline.com/doi/abs/10.1080/13576275.2015.1021314>

Selected articles on organ donation, in the context of end-of-life care, noted in past issues of Media Watch:

- *JOURNAL OF MEDICAL LAW & ETHICS*, 2014;2(2-3):23-35. '**Losing faith in the dead donor rule.**' According to the dead donor rule, vital organs can only be removed from donors already dead. Organ procurement ... must not be the cause of their deaths. The rule purports to protect dying and vulnerable individuals from being sacrificed for the benefit of other people who are in need of those organs. [Noted in Media Watch, 22 September 2014, #376 (p.12)] <http://www.ingentaconnect.com/content/plp/jml/2014/00000002/F0020002/art00002>
- *END OF LIFE JOURNAL*, 2012;2(2). '**The barriers to organ and tissue donation in palliative care.**' This article explores the involvement of palliative care patients in decisions about donating their tissues, why families may be reluctant to consent to donating organs/tissues of deceased loved ones, and reasons why nurses are wary of discussing the possibility of donation with patients and/or their next of kin. [Noted in Media Watch, 9 July 2012, #261 (p.9)] <http://endoflifejournal.stchristophers.org.uk/clinical-review/the-barriers-to-organ-and-tissue-donation-in-palliative-care>

Choice and compassion at the end of life: A critical analysis of recent English policy discourse

SOCIAL SCIENCE & MEDICINE | Online – 12 May 2015 – End-of-life care in England has recently been framed by two very different discourses. One (connected to advance care planning) promotes personal choice, the other promotes compassionate care; both are prominent in professional, policy and media settings. This article outlines the history of who promoted each discourse, from 2008 to 2014, when, why and how this was done. Each discourse is critically analysed from a standpoint that takes account of bodily decline, structural constraints, and human relationality. The authors focus on the biggest group of those nearing the end of their life, namely frail very old people suffering multiple conditions. In their care within contemporary healthcare organisations, choice becomes a tick box and compassion a commodity. Informed choice, whether at

the end of life or in advance of it, does not guarantee the death the person wants, especially for those dying of conditions other than cancer and in the absence of universally available skilled and compassionate care. Enabling healthcare staff to provide compassionate, relational care, however, implies reversing the philosophical, political and financial direction of healthcare in the U.K. and most other Anglophone countries. <http://www.sciencedirect.com/science/article/pii/S0277953615002865>

Extract from Social Science & Medicine article

In their care within contemporary healthcare organisations, choice becomes a tick box and compassion a commodity.

Cont.

Of related interest:

- *EUROPEAN JOURNAL OF CANCER* | Online – 6 May 2015 – ‘**Old age as risk indicator for poor end-of-life care quality: A population-based study of cancer deaths from the Swedish Register of Palliative Care.**’ Old age is a risk indicator for poor end-of-life care quality among cancer patients in Sweden. Age-dependent differences in implementation rate were detected for 10 out of 13 end-of-life care quality indicators, most of which were progressively less well met with each increment in age group. [http://www.ejcancer.com/article/S0959-8049\(15\)00305-6/abstract](http://www.ejcancer.com/article/S0959-8049(15)00305-6/abstract)

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *MODERN HEALTHCARE* | Online – 16 May 2015 – ‘**Assisted-suicide debate focuses attention on palliative, hospice care.**’ About once a week, healthcare providers call the 24-hour palliative-care hotline at the University of Vermont Medical Center with the same basic question: How should they respond to patients who want to take advantage of the state’s new law allowing physicians to prescribe lethal drugs to terminally ill patients who want to die? Dr. Diana Barnard, the hospital’s interim medical director of palliative-care services, sees it as an opportunity to help doctors explore their dying patients’ concerns. She says the law has raised awareness about improving end-of-life care. Many healthcare professionals and patient advocates, regardless of their stance on the emotionally charged issue, hope the ... national debate over physician-assisted suicide will boost awareness and use of palliative care and hospice care. <http://www.modernhealthcare.com/article/20150516/MAGAZINE/305169982>

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 DTDS, underpinned by key principles of therapeutic communication... <http://pmj.sagepub.com/content/20/7/703.abstract>

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 and research tool.

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

Something Missed or Overlooked?

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

Media Watch Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/05/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]

Canada

ONTARIO | HPC Consultation Services (Waterloo Region/Wellington County): <http://hpcconnection.ca/general-resources/in-the-news/>

ONTARIO | Palliative Care Consultation Program (Oakville): <http://www.acclaimhealth.ca/menu-services/palliative-care-consultation/resources/> [Scroll down to 'Additional Resources']

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>

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