

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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Hidden patients: Scroll down to [Specialist Publications](#) and ‘Systematic review of palliative care in the rural setting’ (p.9), in *Cancer Control*.

Canada

Government program funds funerals for British Columbia’s deceased homeless

BRITISH COLUMBIA | *The Globe & Mail* – 1 January 2016 – Homeless in his last days, Joerg Brylla did not leave assets to pay for a lavish funeral and eternal place of rest. But, today, Mr. Brylla’s ashes are behind a brass plate labelled with his name and lifespan – 1945-2014 – in a brick wall at a North Vancouver cemetery. There’s a forest setting and a nearby pond. The cost to inter Mr. Brylla ... was covered by the B.C. government as a part of a program that addresses the fate of the homeless when they die. <http://www.theglobeandmail.com/news/british-columbia/government-program-funds-proper-funerals-for-bcs-deceased-homeless/article27985902/>

Debate over assisted suicide should fuel changes to palliative care, advocates say

THE CANADIAN PRESS | Online – 29 December 2015 – The escalating debate over doctor-assisted death could be the perfect chance for Canada to fix its broken system of palliative care (PC) – a “dark secret” that health advocates say has been quietly deteriorating in the shadows for decades. Terminally ill patients and their family members are forced to take up the slack as a result, said Gabriel Miller, the public issues director of the Canadian Cancer Society, which is scheduled to issue a report next month on the state of PC across the country. “There are thousands of terminally ill Canadians who are not getting the right kind of care,” Miller said. “That’s causing patients and families unnecessary suffering and it is costing the health-care system

precious resources.” Miller is urging the federal Liberal government, along with its provincial and territorial counterparts, to capitalize on the chance to ensure that Canadians have universal access to better, affordable end-of-life care. <http://www.ctvnews.ca/health/debate-over-assisted-suicide-should-fuel-changes-to-palliative-care-advocates-say-1.2716523>

Extract from CTV News report

The Canadian Cancer Society is scheduled to issue a report next month on the state of PC across the country.

N.B. Canada was ranked 11th of 80 countries surveyed in ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ The Economist Intelligence Unit (London, U.K.), October 2015. Commissioned by the Lien Foundation of Singapore [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 1 January 2016 – ‘**If doctors have exhausted every last option, is it ethical to grant a child’s wish to die?**’ Last month, a Canadian advisory panel unnerved many when it boldly – some say recklessly – suggested allowing terminally ill but mentally capable children and mature minors the right to request doctor-assisted death.¹ The provincial-territorial panel says access to an early death shouldn’t be impeded by “arbitrary age limits,” and that eligibility be based on competence, rather than age. <http://news.nationalpost.com/news/canada/if-doctors-have-exhausted-every-last-option-is-it-ethical-to-grant-a-childs-wish-to-die>

1. ‘Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report,’ 30 November 2015. [Noted in Media Watch, 21 December 2015, #441 (pp.3-4)]
file:///C:/Users/admin/AppData/Local/Microsoft/Windows/NetCache/IE/9T1OFYF5/eagreport_20151214_en.pdf

- *LEXOLOGY* | Online – 30 December 2015 – ‘**Carter v Canada (Attorney General).**’ In *Carter* ... the Supreme Court unanimously invalidated the Criminal Code provisions prohibiting physician-assisted suicide (although the preferred nomenclature is “physician-assisted dying” or “medical aid in dying,” because suicide is not illegal in Canada, and the term is therefore stigmatizing). In doing so, the Supreme Court distinguished its 1993 decision in *Rodriguez vs. British Columbia (Attorney General)*, which narrowly upheld these same provisions. But ... the Court suspended the declaration of invalidity for 12 months to allow affected stakeholders to establish a legislative and regulatory response. As such, it is clear that the Court never intended *Carter* should stand on its own as a “guide,” or even a framework, to medical aid in dying in Canada. *Carter* merely provides the minimum constitutional requirements that any medical aid in dying regime in Canada will need to meet. In order to fully appreciate and understand those requirements ... an examination of how the Supreme Court arrived at its decision is warranted. <http://www.lexology.com/library/detail.aspx?g=698ee692-90e9-47f7-9133-0d27291dba55>

Noted in Media Watch, 29 September 2014, #377 (p.2):

- BRITISH COLUMBIA | *The Times-Colonist* (Vancouver) – 20 September 2014 – ‘**What has changed since Sue Rodriguez?**’ In 1993, Sue Rodriguez, suffering unbearably from ALS, challenged the Supreme Court of Canada to let her doctor help her die. The court denied her request, not because it wasn’t the best option for her, but because of the fear that some vulnerable person somewhere, sometime, might be adversely affected by the repercussions of allowing Rodriguez a choice in dying. Lacking hard data to guide their discussion, the judges were clearly divided and ruled five to four against assisted dying. <http://www.timescolonist.com/opinion/op-ed/comment-what-has-changed-since-sue-rodriguez-1.1381969>
- ONTARIO | *Lexology* – 30 December 2015 – ‘**The arrival of assisted dying in Canada: Legal implications for healthcare institutions and professionals.**’ This article ... examines the anticipated impact of *Carter vs. Canada (Attorney General)* on the Ontario healthcare landscape, with reference to stakeholder responses to date, the Quebec Act Respecting End-of-Life Care and, to a lesser extent, the experience of other permissive jurisdictions discussed in *Carter*. This is done in order to consider what issues remain unresolved, what an Ontario framework might look like, and what preparations Ontario physicians and healthcare institutions need to make by 6 February 2016. <http://www.lexology.com/library/detail.aspx?g=5de2d10b-78c0-4762-a50f-328a88e96217>

Specialist Publications

‘The Supreme Court of Canada ruling on physician-assisted death: Implications for psychiatry in Canada’ (p.16), in *Canadian Journal of Psychiatry*.

Cont.

- ONTARIO | *The Ottawa Citizen* – 30 December 2015 – ‘**Ontario plans Ottawa consultations on broad access to assisted suicide.**’ Ottawans will get a say in setting new rules governing assisted suicide... It’s not impromptu, exactly, but there is an element of haste, caused by a Supreme Court decision last winter that gave governments a year to work out how to allow ill adults to end their lives with doctors’ help. The issue is a jurisdictional nightmare: Helping someone end his or her life is forbidden now by federal criminal law, but regulating how doctors will do it is a health-care matter for the provinces, but paying for health care is a joint responsibility (kind of), and national standards require national-level agreement. Somehow the feds and 13 provinces and territories have to get on the same page, and fast. <http://ottawacitizen.com/opinion/columnists/reevely-ontario-plans-ottawa-consultations-on-broad-access-to-assisted-suicide>
- QUEBEC | *Lexology* – 30 December 2015 – ‘**The impact of an act respecting end-of-life care.**’ One of the peculiarities of the Quebec Act that is likely to be amended in the wake of *Carter vs. Canada (Attorney General)* is that it intentionally only legalizes euthanasia by lethal injection and not physician-assisted dying by lethal prescription. As it stands, Quebec is the only jurisdiction in the world to do so. While several other jurisdictions permit both forms of medical aid in dying, some jurisdictions (including all U.S. jurisdictions) only permit lethal prescriptions, and prohibit lethal injections (i.e., U.S. capital punishment notwithstanding). <http://www.lexology.com/library/detail.aspx?g=d2ab2653-6f05-42c3-8e27-ff19948124ad>

U.S.A.

Extra care required when dying parents have young kids

REUTERS | Online – 1 January 2016 – End-of-life care for parents of young children may need to include additional support services that help the entire family cope with terminal illness, a recent study suggests.¹ While all families may struggle when a loved one is dying, parenting duties can create an added layer of emotional stress and complicate efforts to comfort patients at the end of life, researchers note... “What is unique about patients with young children is the extraordinary psychological suffering related to parenting,” said lead study author Dr. Eliza Park, a psychiatry researcher at the University of North Carolina... These parents may worry about how their illness negatively impacts their children’s lives, how their death will impact their

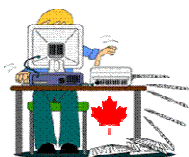
kids, and how to explain their prognosis to their children in an age-appropriate way. They may also experience anticipatory grief about their inability to raise their children into adulthood...

<http://www.reuters.com/article/us-health-terminalcare-parents-idUSKBN0UF22Y20160101>

Extract from University of North Carolina study

38% of mothers had not said goodbye to their children before death and 26% were not at all “at peace with dying.”

1. ‘End-of-life experiences of mothers with advanced cancer: Perspectives of widowed fathers,’ *BMJ Supportive & Palliative Care*, 18 December 2015. [Noted in Media Watch, 28 December 2015, #442 (p.9)] <http://spcare.bmj.com/content/early/2015/12/18/bmjspcare-2015-000976.abstract>



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>

How one couple's loss led to a push for psychological care for kids with cancer

THE WASHINGTON POST | Online – 29 December 2015 – What has stuck with Vicki and Peter Brown for years, beyond the enduring grief of losing their only child, Matthew, are the emotional traumas they all suffered during his struggle with a rare form of bone cancer. Living in a hospital for months on end, Mattie grew anxious and depressed. He feared CT scans and dreaded the sight of another phalanx of white-coated doctors marching down the hall to deliver what invariably was bad news. His parents, frantically trying to save him, struggled with sleepless nights, mounting financial worries – and overwhelming silence that engulfed their Foggy Bottom [Washington DC] home when he died in 2009, at age 7. The Browns often felt lost and alone. “It was just a horrific experience,” Peter Brown said. “And we recognized that the value of psychological, emotional, social support was just as important, if not more important, than the medical treatment.” The couple ultimately

launched a years-long effort to try to ensure that children with cancer and their families get the help they need for the non-medical aspects of the disease. Last week, their hard work paid off with the publication of the first national standards for the “psychosocial” care of children with cancer and their families [see below in this column]. https://www.washingtonpost.com/national/health-science/how-one-couples-loss-led-to-a-push-for-psychological-care-for-kids-with-cancer/2015/12/29/45f0eb86-977e-11e5-b499-76cbe161973_story.html

Specialist Publications

‘Standards for the psychosocial care of children with cancer and their families: An introduction to the special issue’ (p.15), in *Pediatric Blood & Cancer*.

When are you dead? It may depend on which hospital makes the call

THE WASHINGTON POST | Online – 29 December 2015 – The narrow, inscrutable zone between undeniably still here and unequivocally gone includes a range of states that look like life but may not be: a beating heart, a functioning digestive system, even moving fingers and toes. Death is less a moment than a process, a gradual drift out of existence as essential functions switch off, be it rapidly or one by one. ...in 2010, the American Academy of Neurology issued new guidelines for hospitals for determining brain death¹ – the condition that legally demarcates life from whatever lies beyond. Those standards, according to Yale University, neurologist David Greer, who worked on them, are meant to ensure that no patient is declared dead unless they really are beyond all hope of recovery. “This is truly one of those matters of life and death, and we want to make sure this is done right every single time,” he told National Public Radio.² But five years later, according to a study led by Greer ... not all hospitals have adopted the guidelines.³ <https://www.washingtonpost.com/news/morning-mix/wp/2015/12/29/when-are-you-dead-it-may-depend-on-which-hospital-makes-the-call/>

1. ‘Evidence-based guideline update: Determining brain death in adults,’ *Neurology*, 8 June 2010. [Noted in Media Watch, 14 June 2010, #153 (p.11)] <http://www.neurology.org/content/74/23/1911.full.html>
2. ‘Researchers find lapses in hospitals’ policies for determining brain death,’ National Public Radio, 28 December 2015. <http://www.npr.org/sections/health-shots/2015/12/28/460940576/researchers-find-lapses-in-hospitals-policies-for-determining-brain-death>
3. ‘Variability of brain death policies in the U.S.,’ *JAMA Neurology*, 28 December 2015. <http://archneur.jamanetwork.com/article.aspx?articleid=2478467>

Cont. next page

Media Watch: Online

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.17.

Noted in Media Watch, 26 October 2015, #433 (p.15):

- **NEUROCRITICAL CARE** | Online – 21 October 2015 – ‘**Prolonging support after brain death: When families ask for more.**’ The manner in which brain death protocols in the U.S. address family objection to death by neurologic criteria has not been explored. Institutional brain death protocols from hospitals in the U.S. were reviewed to identify if and how the institution addressed situations in which families object to determination of brain death or discontinuation of organ support after brain death. The majority of protocols reviewed did not mention how to handle circumstances in which families object to determination of brain death or discontinuation of organ support after brain death. The creation of guidelines on management of these complex situations may be helpful to prevent distress to families and hospital staff. <http://link.springer.com/article/10.1007/s12028-015-0209-7>

Noted in Media Watch, 20 July 2015, #419 (p.11):

- **BIOETHICS** | Online – 16 July 2015 – ‘**The ethics of continued life-sustaining treatment for those diagnosed as brain-dead.**’ Given the long-standing controversy about whether the brain-dead should be considered alive in an irreversible coma or dead despite displaying apparent signs of life, the ethical and policy issues posed when family members insist on continued treatment are not as simple as commentators have claimed. In this article, the authors consider the kind of policy that should be adopted to manage a family’s insistence that their brain-dead loved one continues to receive supportive care. <http://onlinelibrary.wiley.com/doi/10.1111/bioe.12178/abstract>

When dying alone in prison is too harsh a sentence

THE NEW YORK TIMES | Online OpEd – 28 December 2015 – In our prison system, there are various programs called “compassionate release” or sometimes “medical parole,” whereby elderly or seriously ill prisoners may be released to the community before the end of their sentence. Since 1992, 371 people have been released through the medical parole program in New York State. Only 30 inmates filed applications for medical release in 2014, of whom 17 were released and six died before their review. In the federal prison system the numbers are even more dismal; 101 federal inmates were approved for compassionate release in 2014 out of a total federal prison population of 214,000 people. There are medical reasons, not just compassionate ones, for early release. Providing care to a patient with an illness this serious is complex and prone to error in the best of circumstances. [My patient] needed a palliative care team to do what they do well: develop advanced care plans, identify the patient’s goals of care, aggressively manage pain and other symptoms, and facilitate communication among different specialists. Our aging, ill prisoner population is both a humanitarian crisis and an economic challenge that demands the collaborative attention of physicians, corrections officials, legislators and advocates who can devise national guidelines for medical parole. <http://www.nytimes.com/2015/12/28/opinion/when-dying-alone-in-prison-is-too-harsh-a-sentence.html>

[Prison Hospice Backgrounder](#)

End-of-life care – or the lack of – in the prison system has been highlighted on a regular basis in Media Watch. An updated compilation of the articles, reports, etc., noted in past issues of the weekly report is available on the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/pages/view/3389845/additional-offerings>

Related

- **VERMONT** | Vermont Journalism Trust (Montpelier) – 27 December 2015 – ‘**Lawmakers consider options for aging prisoners, including nursing home care.**’ Vermont’s older prison population has nearly doubled in size over the past 11 years. As of 1 July 2014, 16.1% of Vermont inmates were age 50 or older, up from 8.8% a decade earlier. According to Human Rights Watch, Vermont is part of a national trend. Between 2007 and 2010, the number of prisoners age 65 and up grew by 63%, while the total incarcerated population increased by just 0.7%. As inmates age and their medical needs become more complex, lawmakers and state officials are considering whether the state’s correctional system is well-suited to serve the prison population. <https://vtdigger.org/2015/12/27/lawmakers-consider-options-for-aging-prisoners-including-nursing-home-care/>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- TENNESSEE | *The Tennessean* (Nashville) – 27 December 2015 – **“Death with dignity” law a long shot.** Under Tennessee’s Right to Natural Death Act ... “Every person has the fundamental and inherent right to die naturally and with as much dignity as circumstances permit ...” But the application of that act is very different depending on your circumstances. Consider what might be the difference between these cases: 1) A patient, who relies on a ventilator to be able to breathe, decides she is ready to die. She orders her doctor to remove the ventilator; he does, and she dies soon after; 2) A patient, close to death and suffering from intractable pain that does not respond to medication, asks his doctor to administer palliative sedation. His doctor puts the patient to sleep, removes his intravenous feeding tubes, and the patient dies without waking several days later; and, 3) A terminally ill patient asks his doctor for a prescription for a lethal dose of medication he may take when he determines he no longer wishes to bear the pain and loss of control that his disease causes. Three people who suffer in somewhat similar ways, each wish to end that suffering and say goodbye to his life and his family in a dignified manner and on his own terms, with the aid and counsel of his doctor to ensure the efficacy of his choice. In Tennessee, the actions by the physicians for the first two patients are sanctioned and generally appreciated by the patients’ families. The physician in the third case would face a manslaughter charge regardless of how appreciative the patient and his family might be for the aid offered. <http://www.tennessean.com/story/news/politics/2015/12/27/death-dignity-law-long-shot/77699242/>

International

How Uganda came to earn high marks for quality of death

UGANDA | National Public Radio (U.S.) – 3 January 2016 – Food coloring, water, a preservative and a pound of morphine powder. These are the ingredients in Dr. Anne Merriman’s recipe for liquid morphine. “It’s easier than making a cake,” says Merriman, a British palliative care specialist who founded Hospice Africa in Uganda in 1993 and helped design the formula that hospice workers in Uganda have used for 22 years to craft liquid morphine. The lightest dose, dyed green to indicate the strength and to make sure people don’t confuse it with water, costs about \$2 per bottle to make. Stronger doses are dyed pink and blue. A 16-ounce bottle is about a week’s supply for most patients. Those cheap bottles of green, pink and blue liquid morphine have changed the way people die in Uganda – and are a key reason why Uganda has the best quality of death among low-income countries, according to global Quality of Death Index published by the Economist Intelligence Unit. Back in the 1990s, two of the biggest barriers to good death in Uganda were simple: not enough doctors and not enough morphine. Largely through Merriman’s drive, Hospice Africa Uganda developed professional education in palliative care that would spread the responsibility to nurses, rather than relying on doctors. They helped make it mandatory for medical students in Uganda to study pain management – before Germany did. And Hospice Africa Uganda made liquid morphine. <http://www.npr.org/sections/goatsandsoda/2015/10/16/449243933/how-uganda-came-to-earn-high-marks-for-quality-of-death>

Noted in Media Watch, 16 November 2015, #436 (p.8):

- AFRICA | *The Mail & Guardian* (Nairobi, Kenya) – 9 November 2015 – **‘Morbid but fascinating: The Quality of Death Index, where South Africa and Uganda lead, and Nigeria trails.’** The [Quality of] Index, compiled by the Economist Intelligence Unit,¹ highlights the advances that countries are making in taking care of their citizens at the end of life, as well as the remaining challenges and gaps in policy and infrastructure. It’s morbid, but important stuff – although Africa is still overwhelmingly young, the proportion of older people in the population is rising, and non-communicable diseases such as heart disease, diabetes and cancer are on the rise. The need for long term, palliative care is also therefore set to rise significantly. <http://mgafrica.com/article/2015-11-06-quality-of-death-index>

1. ‘2015 Quality of Death Index: Ranking Palliative Care Across the World,’ Economist Intelligence Unit, October 2015. [Noted in Media Watch, 12 October 2015, #431 (p.6)] http://www.ara.cat/societat/EIU-Quality-Death-Index-FINAL_ARAFIL20151006_0002.pdf

Elderly “reluctant to complain” over health care

U.K. | BBC News – 30 December 2015 – Elderly people are reluctant to make complaints about poor health care or do not know how to, the Parliamentary & Health Service Ombudsman says. A report suggested 56% of people aged over 65 who experienced a problem did not complain because of worries about how it might impact future treatment.¹ Nearly 20% did not know how to raise a complaint, it said, while a third felt complaining would make no difference. Ombudsman Julie Mellor said it could mean some are “suffering in silence.” That could “lead to missed opportunities to improve the service for

others,” she added. The research involved a national survey of almost 700 people over the age of 65, as well as focus groups and case studies. <http://www.bbc.com/news/uk-35196929>

Specialist Publications

‘What facilitates the delivery of dignified care to older people? A survey of health care professionals’ (p.8), in *BMC Research Notes*.

1. ‘Breaking down the barriers: Older people and complaints about health care,’ Parliamentary & Health Service Ombudsman, 30 December 2015. <http://www.ombudsman.org.uk/reports-and-consultations/reports/health/breaking-down-the-barriers>

Noted in Media Watch, 20 October 2014, #380 (p.8):

- U.K. | *The Daily Mail* – 12 October 2014 – **‘National Health Service patients “frightened to complain about poor treatment” because they fear they’ll be branded troublemakers, watchdog finds.’** Despite concerted efforts to make the National Health Service (NHS) more open when things go wrong, Healthwatch has discovered a pervasive “culture of fear” means many patients are still petrified to make complaints.¹ The watchdog is the official voice of the patient in NHS and social care. <http://www.dailymail.co.uk/news/article-2789637/nhs-patients-frightened-complain-poor-treatment-fear-ll-branded-troublemakers-watchdog-finds.html>
 1. ‘Suffering in silence: Listening to consumer experiences of the health and social care complaints system,’ a Healthwatch England Report, October 2014. See ‘Jennifer’s experience...’ (p.21). <http://www.healthwatch.co.uk/sites/default/files/hwe-complaints-report.pdf>

Why Africans in the U.K. pay so much to send relatives’ bodies home

U.K. | BBC News – 30 December 2015 – “My father’s dream was for him to be buried in his birthplace and have the call to prayer resonate over his grave,” says Nadia Elbhiri, whose father passed away last year in London. Ms. Elbhiri, who was born and raised in west London, fulfilled her father’s dream when she repatriated his body to Morocco last year, where he was laid to rest in Larache, a small fishing village in the north of the country. “London was always his home but Morocco was always in his heart,” she says. This desire to be buried in the place you were born is strong for many first generation African migrants in the U.K. The demand is so huge among the British Moroccan community that, according to embassy officials, at least 95% of first generation migrants are buried in Morocco. A system is now in place to cover repatriation costs. <http://www.bbc.com/news/world-africa-35177401>

Noted in Media Watch, 8 December 2014, #387 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 3 December 2014 – **‘From Albania to Zambia: Travel back to country of origin as a goal of care for terminally ill patients.’** Of 336 foreign-born patients [i.e., study participants], 129 expressed a desire to travel to their country of origin; 60 successfully returned to 24 countries. Although patients with the best functional status were most likely to travel successfully, 16 who wanted to travel despite having the worst functional status traveled successfully. There were no deaths *en route* or flight diversions due to medical crisis; all trips were made on regularly scheduled commercial airline flights. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2014.0267>

Cont.

Noted in Media Watch, 18 August 2014, #371 (p.11):

- *SUPPORTIVE CARE IN CANCER* | Online – 16 August 2014 – ‘**I want to fly home: A terminal cancer patient’s right to go home.**’ As palliative care physicians, we sometimes find ourselves immersed in the dilemma of a patient with terminal cancer requesting to fly back home, often overseas. This particular situation is filled with an array of complex variables: establishing that the medical condition is stable enough for overseas travel, dealing with a significant cost, securing proper care on the receiving end, symptom management during flight, and dealing with the possibility of in-flight death, among others. <http://link.springer.com/article/10.1007/s00520-014-2391-0>

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

What facilitates the delivery of dignified care to older people? A survey of health care professionals

BMC RESEARCH NOTES | Online – 28 December 2015 – Whilst the past decade has seen a growing emphasis placed upon ensuring dignity in the care of older people this policy objective is not being consistently achieved and there appears a gap between policy and practice. We need to understand how dignified care for older people is understood and delivered by the health and social care workforce and how organisational structures and policies can promote and facilitate, or hinder, the delivery of such care. 79% of survey respondents identified factors within their working environment that helped them provide dignified care and 68% identified barriers to achieving this policy objective. Facilitators and barriers to delivering dignified care were categorised into three domains: “organisational level”, “ward level,” and “individual level.” Within these levels, respondents reported factors that both supported and hindered dignity in care including “time,” “staffing levels,” training,” “ward environment,” “staff attitudes,” “support,” “involving family/carers,” and “reflection.” Facilitators and barriers to the delivery of dignity as perceived by health and social care professionals are multi-faceted and range from practical issues to interpersonal and training needs. Thus interventions to support health and social care professionals in delivering dignified care, need to take a range of issues into account to ensure that older people receive a high standard of care in National Health Service Trusts. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4693419/>

Selected articles on dying with dignity

- *JOURNAL OF CLINICAL NURSING* | Online – 23 February 2015 – ‘**Dignity-conserving care in palliative care settings: An integrative review.**’ Thirty-one articles were included. Nine dignity model themes were used to classify care actions: 1) Level of Independence; 2) Symptom distress; 3) Dignity-conserving perspectives; 4) Dignity-conserving practices; 5) Privacy boundaries; 6) Social Support; 7) Care tenor; 8) Burden to others; and, 9) Aftermath concerns. [Noted in Media Watch, 2 March 2015, #399 (p.8)] <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12791/abstract>
- *JOURNAL OF HOSPICE & PALLIATIVE MEDICINE*, 2004;21(2):116-120. ‘**Dying with dignity: The good patient versus the good death.**’ The purpose of this review was two-fold: first, to develop an understanding of “dying with dignity” to enhance the end-of-life care received by dying patients and, second, to contribute to a concept analysis of dignity to improve the clarity and consistency of future research related to dignity in aging individuals. [Noted in Media Watch, 26 January 2015, #394 (p.15, under ‘Worth Repeating’)] <http://ajh.sagepub.com/content/21/2/116.short>
- *PALLIATIVE MEDICINE* | Online – 31 March 2014 – ‘**An integrative review of dignity in end-of-life care.**’ The meaning of dying with dignity is ambiguous... Themes of dying with dignity are: 1) A human right; 2) Autonomy and independence; 3) Relieved symptom distress; 4) Respect; 5) Being human and being self; 6) Meaningful relationships; 7) Dignified treatment and care; 8) Existential satisfaction; 9) Privacy; and, 10) Calm environment. Factors influencing dignity include demographic, illness-related, and treatment-/care-related factors, as well as communication. [Noted in Media Watch, 7 April 2014, #352 (p.13)] <http://pmj.sagepub.com/content/early/2014/03/31/0269216314528399.abstract>

Systematic review of palliative care in the rural setting

CANCER CONTROL, 2015;22(4):450-464. Research has informed the development of professional guidelines and integration of the principles of palliation into oncology care, from the time of diagnosis to end of life among patients with curable cancers, high symptom burden, and metastatic disease alike. However, the rural setting has created a barrier for these advances to reach patients not located near specialty centers. This global issue has been recognized and efforts are being initiated to discover novel strategies to ensure high-quality palliative and end-of-life care can reach those living in rural communities. Telehealth, community health workers, specialists trained in various health care fields, and other volunteers trained in the approaches of palliative care (PC) have shown promise in bringing complex comfort strategies to many remote regions... In addition, the ability to educate all of the health care professionals working in rural settings presents challenges that are surmountable. Organized efforts do exist for bringing PC skills to rural health clinicians and

care settings. Shortages of PC specialists are a reality, even in urban areas. Hence, every clinician should have a basic set of primary PC skills of communication, advance care planning, and symptom control to ensure high-quality care for all persons with cancer and their families. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/BXO49UAX/450.pdf>



'End-of-life care in rural communities.'
<http://www.ruralontarioinstitute.ca/blog/post/End-of-life-care-in-rural-communities.aspx>

'National palliative medicine survey looks at urban versus rural.'
<http://www.ruralontarioinstitute.ca/blog/post/National-palliative-medicine-survey-looks-at-urban-versus-rural.aspx>

N.B. Additional articles on end-of-life care in rural communities and remote regions are noted in the issues of the *Media Watch* of 30 November 2015, #438 (p.12); 14 September 2015, #427 (p.8); 7 September 2015, #426 (p.17); 17 August 2015, #423 (p.14), 11 May 2015, #409 (p.13), and 30 June 2014, #364 (p.15).

King's College London Student Clinical Ethics Committee case discussion: A family requests that their grandmother, who does not speak English, is not informed of her terminal diagnosis

CLINICAL ETHICS | Online – 29 December 2015 – The case study summarises the reflections of the Committee and focuses on the role of cultural norms in healthcare decision making, the extent to which the views of the family about what is best for the patient should be respected, whether the patient should have been informed of her terminal diagnosis and the role of the clinician in navigating complex family dynamics. <http://cet.sagepub.com/content/early/2015/12/24/1477750915622036.abstract>

Helping lay carers of people with advanced cancer and their GPs to talk: An exploration of Australian users' views of a simple carer health checklist

HEALTH & SOCIAL CARE IN THE COMMUNITY | Online – 23 December 2015 – The lay caregiving role is integral to advanced cancer care but places carers' health at risk. A supportive general practitioner (GP) can help primary lay carers manage their health, if they disclose their concerns. A Needs Assessment Tool for Caregivers (NAT-C) was developed for carers to self-complete and use as the basis of a GP consultation, then tested in a randomised controlled trial. Three major themes were identified: 1) Acceptability of the intervention; 2) Impact of the intervention on the GP-patient relationship; and, 3) Place of the intervention in advanced cancer care. This simple checklist was acceptable to carers, although some were uncertain about the legitimacy of discussing their own needs with their GP. Carer-patients could not be certain whether a GP would be willing or equipped to conduct a NAT-C-based consultation. Such consultations were acceptable to most GPs, although some already used a holistic approach while others preferred brief symptom-based consultations. Although the NAT-C was acceptable to most carers and GPs, supportive consultations take time. This raises organisational issues to be addressed so carers can seek and benefit from their GP's support. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12312/abstract>

Death anxiety among nurses and health care professionals: A review article

INTERNATIONAL JOURNAL OF COMMUNITY BASED NURSING & MIDWIFERY, 2016;4(1):1-10. There has been an increasing recognition of the importance of death education for nursing and allied health professionals. Coincident with the need for heightened training in optimizing death and dying care are curriculum that addresses emotion awareness and regulation for providers. Given the tendencies for the modern health care enterprise to focus on prolonging life, it is not surprising that death and dying curriculum exposure have not been prioritized or uniformly applied in educational programs. Globally a large number of patients continue to die in hospital or nursing home settings despite preferences to die in home environments. It is recommended that programs on death education be expanded, with a focus on the multi-faceted experience of death anxiety as a normative occurrence for health care workers. These programs need to occur not only in the formative educational process, but also as a part of orientation for new staff members, and as refreshers for more experienced nurses. Such an emphasis may reduce the culture of death as a taboo topic for health care workers, and may increase quality of communications and thus perceptions of care between health care professionals and their patients and family members. <file:///C:/Users/admin/AppData/Local/Microsoft/Windows/INetCache/IE/CO7JBP8D/304-1670-2-PB.pdf>

Noted in Media Watch, 4 February 2013, #291 (p.11):

- *OPEN NURSING JOURNAL* | Online – 24 January 2013 – ‘**How death anxiety impacts nurses’ caring for patients at the end of life: A review of literature.**’ Three key themes identified were: 1) Nurses’ level of death anxiety; 2) Death anxiety and attitudes towards caring for the dying; and, 3) death education was necessary for such emotional work. Results suggested that the level of death anxiety of nurses working in hospitals in general, oncology, renal, hospice care or in community services was not high. <http://www.benthamsience.com/open/tonursj/openaccess2.htm>

Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of “current thinking” on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy, research and teaching tool.

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Something Missed or Overlooked?

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

How defining clinical practices may influence their evaluation: The case of continuous sedation at the end of life

JOURNAL OF EVALUATION IN CLINICAL PRACTICE | Online – 29 December 2015 – Continuous sedation ... is an end-of-life practice that has gained considerable attention in the international literature. Nevertheless, significant confusion persists, even on how to label or define the practice. Several different terms and definitions exist, and these are often non-neutral and indicative of one's normative position on sedation at the end of life. This is problematic for two reasons. First, the use of such value-laden terms or definitions of continuous sedation may make it difficult, if not impossible, to agree on the facts surrounding continuous sedation. Second, including normative criteria in a definition can lead one to make disguised circular or tautological statements. Two commonly used terms, "palliative sedation" and "terminal sedation," have been strongly criticized. The authors propose to use another, more descriptive term, namely "continuous sedation at the end of life." As regards the different definitions of sedation, some are general, but most contain very specific elements, thereby clearly limiting the number of cases that are covered by the definition. Some definitions of sedation include the intention one should (not) have, the possible indications for the practice, and the type of patients the practice should be reserved for. Including value-laden elements in the very definition of a clinical practice runs the risk of pre-empting a proper normative debate about the practice. The authors explain why this is the case and why it is problematic, and we propose an alternative, descriptive, definition that seeks to avoid these problems. <http://onlinelibrary.wiley.com/doi/10.1111/jep.12503/abstract>

Related

- *MEDICINE, HEALTH CARE & PHILOSOPHY* | Online – 29 December 2015 – '**Continuous deep sedation and homicide: An unsolved problem in law and professional morality.**' When a severely suffering dying patient is deeply sedated, and this sedated condition is meant to continue until his death, the doctor involved often decides to abstain from artificially administering fluids. For this dual procedure almost all guidelines require that the patient should not have a life expectancy beyond a stipulated maximum number of days (4–14). The reason obviously is that in case of a longer life-expectancy the patient may die from dehydration rather than from his lethal illness. But no guideline tells us how we should describe the dual procedure in case of a longer life-expectancy. <http://link.springer.com/article/10.1007/s11019-015-9680-3>

Palliative sedation in pediatric patients: Guidelines established by the pediatric palliative consultation service at Sainte-Justine hospital, Montréal, Québec

MÉDECINE PALLIATIVE | Online – 29 December 2015 – The decision to induce palliative sedation (PS) must be based on a rigorous process and allow discussions to reach a consensus within the interdisciplinary team. The objective is patient comfort... PS is not intended to hasten death... Continuous PS is rarely used in pediatrics. Recommended criteria: 1) Ensure symptoms are really refractory; 2) Conduct an interdisciplinary meeting; 3) Conduct a meeting with the family (and patient if he/she is apt); and, 4) Decide on type and level of sedation. Adequate monitoring and comfort care should be provided at all times to the patient. Assistance and support of family is paramount throughout the decision-making process and course of sedation. PS must be supervised by medical and pharmacological guidelines and an institutional policy. <http://www.sciencedirect.com/science/article/pii/S1636652215001889>

N.B. French language article.

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.**' <http://ajh.sagepub.com/content/early/2015/10/05/1049909115609294.abstract>

Cont.

Selected articles on continuous sedation at the end of life

- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 5 November 2015 – ‘**A survey of hospice and palliative care physicians regarding palliative sedation practices.**’ Nearly all respondents indicated palliative sedation may be used for refractory symptoms and acceptable by 26% only for imminently dying patients. [Noted in Media Watch, 9 November 2015, #435 (p.11)] <http://ajh.sagepub.com/content/early/2015/11/04/1049909115615128.abstract>
- *EUROPEAN JOURNAL OF CANCER CARE* | Online – 29 October 2015 – ‘**Reasons for continuous sedation until death in cancer patients: A qualitative interview study.**’ Findings indicate that medical decision-making for continuous sedation is not only based on clinical indications, but also related to morally complex issues such as the social context and the personal characteristics and preferences of individual patient and their relatives. [Noted in Media Watch, 9 November 2015, #435 (p.11)] <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12405/abstract>
- *AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 May 2014 – ‘**Palliative sedation: Analysis of international guidelines and position statements.**’ Guidelines, etc., have been published by the 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). [Noted in Media Watch, 12 May 2014, #357 (p.6)] <http://ajh.sagepub.com/content/32/6/660>

Ask early and often: Offering better palliative care

JOURNAL OF THE NATIONAL CANCER INSTITUTE, 2016;108(1). What is the biggest misconception on palliative care (PC)? If you ask any PC specialist, you are likely to hear the same answer: PC is only for patients nearly at the end of life. Although that misconception is shrinking among both clinicians and patients, there is a long way to go to broaden access to supportive care that can minimize symptoms and boost quality of life. Many clinical trials have shown the benefits of adding PC in conjunction with potentially curative therapies. “The tension for a cancer center to emphasize PC is profound,” said Kathleen M. Foley MD ... at Memorial Sloan-Kettering Cancer Center in New York who specializes in pain management and PC. “A cancer center wants to be a cure center and to receive research funding for curative therapies. But my stance has always been that we can do both. Because the combination of potentially curative care together with alleviating symptoms and addressing a patient’s quality of life – that is the best cancer care. Step by step, we are learning that we can care and cure at the same time.” Jennifer Temel MD., of Massachusetts General Hospital in Boston, and colleagues carried out a ... study in metastatic lung cancer patients.¹ Patients who received PC in addition to chemotherapy had better quality of life and were less likely to be depressed and receive aggressive treatment in the last few weeks of life. Most important, patients randomized to PC lived longer, with a median overall survival of 11.6 months, compared with 8.9 months in the standard therapy arm. <http://jnci.oxfordjournals.org/content/108/1/djv420.extract>

1. ‘Early palliative care for patients with metastatic non-small-cell lung cancer, *The New England Journal of Medicine*, 2010;363(8):733-742. [Noted in Media Watch, 23 August 2010, #163 (p.8)] <http://www.nejm.org/doi/full/10.1056/NEJMoa1000678#t=articleTop>

[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 knowledge 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>

Why do home hospice patients return to the hospital? A study of hospice provider perspectives

JOURNAL OF PALLIATIVE MEDICINE | Online – 24 December 2015 – Hospice provides an opportunity for patients to receive care at home at the end of life (EOL); however, approximately 25% of patients who disenroll from hospice are hospitalized. Hospitalization can lead to poor care transitions and result in unwarranted care and adverse patient outcomes. Research examining reasons for hospitalization in this patient population is limited. Eight major themes were identified: 1) Not fully understanding hospice; 2) Lack of clarity about disease prognosis; 3) Desire to continue receiving care from non-hospice physicians and hospital; 4) Caregiver burden; 5) Distressing/difficult-to-manage signs and symptoms; 6) Caregivers' reluctance to administer morphine; 7) 911's faster response time compared to hospice; and, 8) Families' difficulty accepting patients' mortality. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2015.0178>

Noted in Media Watch, 9 June 2014, #361 (p.11):

- *PALLIATIVE MEDICINE*, 2014;28(7):917-918. '**Avoidable for whom? Hospital use at the end of life.**' The use of health services by people with palliative care needs has come under particular scrutiny. Indeed, a policy concern in many countries is reducing the number, and length, of acute hospital admissions among people who are at the end of life. This is typically presented as a "win-win" situation as a "good death" is viewed as hard to achieve in a hospital setting. However, papers in this edition [of *Palliative Medicine*] add to a growing body of evidence which indicates that, while this argument may appear both appealing and straightforward on paper, the realities of dying are more complex and unpredictable.^{1,2} <http://pmj.sagepub.com/content/28/7/917.extract>
 1. 'What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses,' *Palliative Medicine*, 2014;28(7):941-948. [Noted in Media Watch, 24 February 2014, #346 (p.13)] <http://pmj.sagepub.com/content/28/7/941.abstract>
 2. 'General practitioners' perspectives on the avoidability of hospitalizations at the end of life: A mixed method study,' *Palliative Medicine*, 2014;28(7):949-958. [Noted in Media Watch, 7 April 2014, #352 (p.13)] <http://pmj.sagepub.com/content/early/2014/04/02/0269216314528742.abstract>

Noted in Media Watch, 14 April 2014, #353 (p.12):

- *JOURNAL OF PALLIATIVE MEDICINE* | Online – 7 April 2014 – '**Rehospitalization of older adults discharged to home hospice care.**' Among those patients [i.e., study participants] readmitted, 25% had received a palliative care consultation, compared to 47.1% of those not readmitted. Patients without a participating decision-maker involved in their hospice decision had 3.5 times the risk of readmission within 30 days, compared to those with. Patients who had one or more telephone contacts with their primary care physician during week one after discharge had 2.4 times the readmission risk within 30 days, compared to patients with no such contacts during this period. Readmission within 30 days of initial discharge to hospice is associated with several measures of care and care planning. <http://online.liebertpub.com/doi/abs/10.1089/jpm.2013.0224>

End-of-life decision-making for people with intellectual disability from the perspective of nurses

JOURNAL OF POLICY & PRACTICE IN INTELLECTUAL DISABILITIES, 2015;12(4):294-302. Little is known about the involvement of nurses in the process of making end-of-life decisions for people with intellectual disability (ID). The aim of this study was to clarify this process from the perspective of nurses. The core characteristic of the position of the nurses [i.e., study participants] and of the way they supported the patient was "Being at the center of communication." Related categories of topics emerging from the interviews were "Having a complete picture of the patient," "Balancing involvement and distance," "Confidence in one's own opinion," and "Knowledge about one's own responsibility," all of which were focused on the patient. This focus ... might explain why the nurses could make valuable contributions to such an important subject as end-of-life decisions. People with ID themselves were not involved in the decisions. The nurses were not always aware who was ultimately responsible for the end-of-life decisions. <http://onlinelibrary.wiley.com/doi/10.1111/jppi.12140/abstract>

Cont.

Noted in Media Watch, 2 June 2014, #360 (p.10):

- *PATIENT EDUCATION & COUNSELING* | Online – 23 May 2014 – ‘**Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: A national survey of the considerations and beliefs of GPs, intellectual disabilities physicians and care staff.**’ Quality of life and wellbeing were also frequently considered in both decisions to start/continue an intervention and decisions to forgo/withdraw an intervention. Seventy per cent believed that people with intellectual disabilities should always be informed about interventions, and 61% would respect a refusal by the person. [http://www.pec-journal.com/article/S0738-3991\(14\)00194-3/abstract](http://www.pec-journal.com/article/S0738-3991(14)00194-3/abstract)

Related

- *RESEARCH IN DEVELOPMENTAL DISABILITIES*, 2016;49-50:235-246. ‘**End-of-life decision-making for children with severe developmental disabilities: The parental perspective.**’ In this review, the authors identified nine studies that met all inclusion criteria. Parental involvement in end-of-life decision-making varied widely, ranging from having no involvement to being the sole decision-maker. Most preferred to actively share in the decision-making process regardless of their child’s specific diagnosis or co-morbidity. The main factors that influenced their decision-making were their strong urge to advocate for their child’s best interests and to make the best (possible) decision. In addition, parents felt influenced by their child’s visible suffering, remaining quality of life and the will they perceived in their child to survive. <http://www.sciencedirect.com/science/article/pii/S0891422215300299>

Prescribing red wine: An Rx for the end of life

MEDSCAPE | Online – 30 December 2015 – The Clermont-Ferrand University Hospital in France offers a wine bar to palliative care (PC) patients and families “to help them relax and speak freely ... in an attempt to restore longing, taste, desire and even pleasure.” The center director who proposed the bar, Dr. Virginie Guastella, is quoted as saying, “It’s a way of rethinking the care of others, taking into account their feelings and emotions that make them a human being.” The wine is reportedly donated and is served according to an institutional protocol. A wine-benefits training program helps staff identify ways in which wine enhances well-being. “Medically supervised” wine tasting with patients near the end of life is currently illicit in most healthcare institutions. A review of websites from The Joint Commission, the American Heart Association, the Centers for Medicare & Medicaid Services, and the National Hospice & Palliative Care Organization finds no mention of it. <http://www.medscape.com/viewarticle/856346>

N.B. Access requires a subscription.

Noted in Media Watch, 4 August 2014, #369 (p.5):

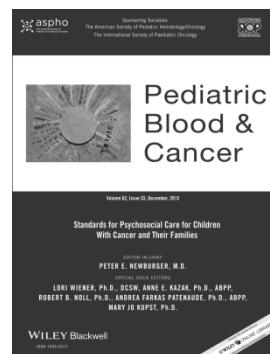
- FRANCE | *The Independent* (U.K.) – 31 July 2014 – ‘**French hospital to open wine bar for patients as doctor defends the “right to have fun.”**’ Fine wines, champagne and whisky will be among the choices at the unusual establishment being opened in September. The bar will be in the palliative care centre at Clermont-Ferrand University Hospital in Puy-de-Dôme, which offers comfort for people with chronic and terminal illnesses. Dr. Virginie Guastella ... said she was defending “the right to have fun” and hopes the idea will catch on in other hospitals to brighten up the lives of patients and their families. <http://www.independent.co.uk/life-style/health-and-families/health-news/french-hospital-to-open-wine-bar-for-patients-as-doctor-defends-the-right-to-have-fun-9641920.html>

Noted in Media Watch, 7 December 2009, #126 (p.4):

- AUSTRALIA (New South Wales) | *The Sydney Morning Herald* – 5 December 2009 – ‘**Doctor’s orders: For medicinal purposes only.**’ In the palliative care ward of Greenwich Hospital, Happy Hour starts at 11 a.m. This is when John Whalan, a volunteer, begins pushing his trolley, garlanded with leis and clinking with bottles of brandy and gin, through the ward, mixing tall ones for the terminally ill. <http://www.smh.com.au/national/doctors-orders-for-medicinal-purposes-only-20091204-kaxx.html>

Standards for the psychosocial care of children with cancer and their families: An introduction to the special issue

PEDIATRIC BLOOD & CANCER, 2015;62(S5):S419-S424. Pediatric oncology psychosocial professionals collaborated with an interdisciplinary group of experts and stakeholders and developed evidence-based standards for pediatric psychosocial care. Given the breadth of research evidence and traditions of clinical care, 15 standards were derived. Each standard is based on a systematic review of relevant literature and used the Appraisal of Guidelines for Research & Evaluation II process to evaluate the quality of the evidence. This article describes the methods used to develop the standards and introduces the 15 articles included in this special issue. Established standards help ensure that all children with cancer and their families receive essential psychosocial care. <http://onlinelibrary.wiley.com/doi/10.1002/pbc.25675/abstract>



N.B. Special issue contents page: <http://onlinelibrary.wiley.com/doi/10.1002/pbc.v62.S5/issuetoc>

Noted in Media Watch, 4 May 2015, #408 (p.14):

- *PALLIATIVE MEDICINE* | Online – 28 April 2015 – ‘Establishing psychosocial palliative care standards for children and adolescents with cancer and their families...’ Integration of patient, parent and clinician perspectives on end-of-life needs reveal mutual themes: 1) Holding to hope; 2) Communicating honestly; 3) Striving for relief from symptom burden; and, 4) Caring for one another. Shared priorities included: 1) Care access; 2) Cost analysis; 3) Social support to include primary caregiver support; 4) Sibling care; 5) Bereavement outreach; 6) Symptom assessment and interventions to include physical and psychological symptoms; 7) Communication approaches to include decision-making; and, 8) Overall care quality. <http://pmj.sagepub.com/content/early/2015/04/22/0269216315583446.abstract>

Palliation: A concept analysis

RESEARCH & THEORY FOR NURSING PRACTICE, 2015;29(4):297-305. Palliation is a term that is used in the literature to identify very different concepts. It is often used interchangeably with palliative care, symptom management, and hospice. While these concepts are indeed related, the distinctions are valuable to identify to impact patient care. A concept analysis of palliation ... to define, identify core attributes, and suggest areas for further research related to palliation ... resulted in the following definition of palliation: patient goal directed symptom relief from a non-curative intervention, administered via human presence. Clarification of the definition and attributes will facilitate continued efforts to design valid measures of palliation as a patient-centered outcome. <http://www.ncbi.nlm.nih.gov/pubmed/26714356>

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MW 400: Palliative care in advanced lung disease: The challenge of integrating palliation into everyday care
Download the complete issue (PDF, 450 KB)

CHEST | Online - 5 March 2015 | The tendency toward "either/or" thinking (either care or comfort) in traditional biomedical care paradigms does little to optimize care in advancing chronic illness. Calls for improved palliation in chronic lung disease mandate a re-examination of related care gaps and current clinical practices. [read more...](#)

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

Protecting the digital afterlife: Virginia's Privacy Expectation Afterlife & Choices Act

RICHMOND JOURNAL OF LAW & PUBLIC INTEREST | Online – Accessed 28 December 2015 – In the digital age, our presence lives on through social media and electronic communications long after our death. Grappling with privacy concerns, effective estate administration, compliance with federal law, and personal wishes of the deceased, lawmakers and industry leaders have struggled to determine the best course of action for access to these accounts and communications. Virginia's Privacy Expectation Afterlife & Choices Act (PEAC) provides access in a way that hopes to preserve our privacy rights while allowing fiduciaries to carry out estate administration duties. More concerns in this area of the law are sure to arise, but Virginia's adoption of PEAC gives citizens of the Commonwealth better clarity regarding their digital afterlife. <http://scholarship.richmond.edu/cgi/viewcontent.cgi?article=1325&context=jolpi>



Noted in Media Watch, 28 July 2014, #368 (p.2):

- U.S. | National Public Radio – 23 July 2014 – ‘**A plan to untangle our digital lives after we’re gone.**’ As we live more and more of our lives online, more and more of what used to be tangible turns digital. “Where you used to have a shoebox full of family photos, now those photos are often posted to a website,” notes Ben Orzeske, legislative counsel at the Uniform Law Commission. That shoebox used to go to the executor of the deceased’s will, who would open it and distribute its contents to family members. The will’s author could decide what she wanted to give and to whom. The [Federal] Uniform Fiduciary Access to Digital Assets Act aims to make the digital shoebox equally accessible. <http://www.npr.org/blogs/alltechconsidered/2014/07/23/334051789/a-plan-to-untangle-our-digital-lives-after-were-gone>

Is it possible to detect an improvement in cancer pain management? A comparison of two Norwegian cross-sectional studies conducted 5 years apart

SUPPORTIVE CARE IN CANCER | Online – 28 December 2015 – In recent years, efforts were undertaken to achieve better cancer pain management, e.g., clinical research, new treatment modalities, development of guidelines, education and focus on implementation. The aim of the present study was to compare the prevalence and characteristics of pain and breakthrough pain between cross-sectional studies conducted in 2008 and 2014. It was hypothesized that an improvement in pain control would be observed the years in between. Unexpectedly, none was observed. Efforts are still needed to improve cancer pain management. <http://link.springer.com/article/10.1007/s00520-015-3064-3>

Assisted (or facilitated) death

Representative sample of recent news media coverage:

- *CANADIAN JOURNAL OF PSYCHIATRY*, 2015;60(12):591-596. ‘**The Supreme Court of Canada ruling on physician-assisted death: Implications for psychiatry in Canada.**’ This paper aims to stimulate discussion about psychiatry’s role in this heretofore illegal practice and to explore how psychiatry might become involved in end-of-life care in a meaningful, patient-centred way. The author reviews existing international legislation and professional regulatory standards regarding psychiatry and physician assisted death. She then goes on to discuss important challenges psychiatry might face regarding capacity assessment, the notion of rational suicide, and the assessment of suffering. <http://search.proquest.com/openview/de1916ab771d75990eb1c9727d92baca/1?pq-origsite=gscholar&cbl=35547>

Noted in Media Watch, 22 September 2015, #428 (p.3):

- CANADA | *The Star-Phoenix* (Saskatoon, Saskatchewan) – 14 September 2015 – ‘**Psychiatrists fear role as “suicide enablers.”**’ The Supreme Court of Canada ruling is creating deep discomfort in a field of medicine where “cures” are rare and where many worry there is every possibility severe depression and other mental illnesses could meet the test for assisted suicide ... as set out by the court. <http://www.thestarphoenix.com/health/psychiatrists+fear+role+suicide+enablers/11361752/story.html>

Cont.

From the archives:

- *THE HASTINGS REPORT*, 1998;28(4):24-31. ‘Should psychiatrists serve as gatekeepers for physician-assisted suicide?’ Mandating psychiatric evaluation for patients who request physician-assisted suicide may not offer the clear cut protection from possible coercion or other abuse that proponents assert. Competence itself is a complex concept and determinations of decision making capacity are not straightforward, nor is the relationship between mental illness and decision making capacity in dying patients clearly understood. And casting psychiatrists as gatekeepers in end-of-life decisions poses risks to the profession itself. <http://onlinelibrary.wiley.com/doi/10.2307/3528610/abstract>

Worth Repeating

Discussing treatment preferences with patients who want “everything”

ANNALS OF INTERNAL MEDICINE, 2009;151(5):345-349. When asked about setting limits on medical treatment in the face of severe illness, patients and their families often respond that they want “everything.” Clinicians should not take this request at face value, but should instead use it as the basis for a broader discussion about what “doing everything” means to the patient. The discussion might include questions about what balances of treatment burden and benefit the patient can tolerate and about emotional, cognitive, spiritual, and family factors that underlie the request. After this initial exploration, the clinician can propose a philosophy of treatment and make recommendations that capture the patient’s values and preferences in light of the medical condition. Clinicians should respond to emotional reactions, directly negotiate disagreements, and use harm-reduction strategies for the relatively infrequent instances in which patients continue to request burdensome therapy that is unlikely to help. By using this approach, patients, families, and clinicians will be better able to understand each other and join together to develop a treatment approach that best respects patient and family values in light of what is medically achievable. <http://www.annals.org/cgi/content/abstract/151/5/345>

Media Watch: Online

International

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/publications/newsletter/2015/12/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]

Cont.

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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