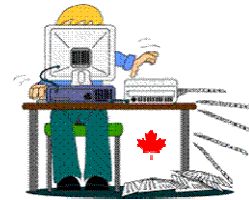


## **Media Watch...**

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.

**13 April 2015 Edition | Issue #405**



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**Compiled & Annotated by Barry R. Ashpole**

**The illness experience: Scroll down to [Specialist Publications](#) and ‘Concordance between experiences of bereaved relatives, physicians, and nurses with hospital end-of-life care: Everyone has their “own truth”’ (p.9), in *International Journal of Palliative Care*.**

## **Canada**

### **End-of-life care in Ontario**

#### **Last month of life costs health-care system \$14K on average: Report**

ONTARIO | *The National Post* – 7 April 2015 – The average person generates \$14,000 in health-care costs during the last 30 days of his or her life, often receiving high-impact hospital treatment that may only make their passing more difficult, concludes a new Canadian study.<sup>1</sup> The landmark research, a rare attempt to put a price tag on the care that immediately precedes death, highlights the need to shift treatment of the dying out of acute-care facilities, argue the authors. Analysis of Ontario data found that close to \$5 billion a year is spent in that province alone on the care of people in their last year – about 10% of the overall health budget – and \$1.3 billion on their last month. Close to half that expense stems from admission to acute-care hospitals, despite widespread agreement that many patients should get palliative or home care in their final days. <http://news.nationalpost.com/news/canada/ast-month-of-life-costs-health-care-system-14k-on-average-report>

#### **Extract from *The National Post* report**

[Peter] Tanuseputro and colleagues from the Universities of Toronto and Ottawa said their analysis of health-care data in Ontario from 2010-2013 may be the first to examine end-of-life spending across a variety of health sectors for such a large population.

#### **Specialist Publications**

**‘Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians’** (p.9), in *JAMA Internal Medicine*.

#### **Media Watch Online**

Media Watch (or a link to the weekly report) is posted on a number of websites that serve the hospice and palliative care community-at-large. Complete listing p.12.

Cont.

1. 'The health care cost of dying: A population-based retrospective cohort study of the last year of life in Ontario, Canada,' *PlosOne*, 26 March 2015. The study is descriptive in nature and does not directly address quality of care; nevertheless, it can be inferred that a proportion of health care utilization near the end of life, such as certain emergency room visits, hospital admissions and medications, are potentially preventable and burdensome for the patient. <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0121759>

## **Assisted (or facilitated) death**

Representative sample of recent news media coverage:

- *THE NATIONAL POST* | Online – 10 April 2015 – '**How to end a life? Canada can look abroad for guidance as it seeks best method for assisted suicide.**' Leaders of the Canadian Medical Association are turning to European and U.S. jurisdictions that have legalized doctor-hastened death as they begin to wrap their minds around the sheer practicalities and technical aspects. <http://news.nationalpost.com/news/canada/canadian-politics/how-to-end-a-life-canada-can-look-abroad-for-guidance-as-it-seeks-best-method-for-assisted-suicide>

Noted in Media Watch, 6 April 2015, #404 (p.2):

- *THE NATIONAL POST* | Online – 1 April 2015 – '**Canadian medical schools readying doctors to talk to patients about assisted suicide.**' As the nation moves toward legalized physician-assisted death, Canada's seventeen faculties of medicine have begun to consider how they will introduce assisted dying into the curriculum for the next generations of doctors. <http://news.nationalpost.com/health/assisted-death-medical-schools>

## **U.S.A.**

### **No legally appointed surrogate decision maker**

#### **Many very ill patients choose "next of kin" who aren't, study finds**

CONNECTICUT | *U.S. News & World Report* – 7 April 2015 – Nearly one out of 10 veterans in Connecticut younger than 65 have chosen someone who is not part of their immediate family as their next of kin, a new study reports.<sup>1</sup> Immediate – or nuclear – family generally includes a person's spouse, adult child, parent or sibling. However, state laws won't allow non-immediate family members to make medical decisions on behalf of the patients, unless the patients have specifically named them in a living will or other legal document, said lead author Dr. Andrew Cohen, a postdoctoral fellow at the Yale University School of Medicine in New Haven, Connecticut. This could cause delays and confusion over crucial medical care needed to treat a personal health crisis, he said. And, under current laws, it's possible that a family member with little to no participation in a person's day-to-day life could end up responsible for making life-and-death medical decisions on that person's behalf, according to the researchers. <http://health.usnews.com/health-news/articles/2015/04/07/many-very-ill-patients-choose-next-of-kin-who-arent-study-finds>

1. 'Patients with next-of-kin relationships outside the nuclear family,' *Journal of the American Medical Association*, 2015;313(13):1369-1370. For patients who lose capacity and have no legally appointed surrogate decision maker, most states have laws that specify a hierarchy of persons who may serve as same. <http://jama.jamanetwork.com/article.aspx?articleid=2214076>

### **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>

## Prison hospice

### **Oscar nomination opening prison doors to Fox Valley filmmaker**

ILLINOIS | *The Chicago Tribune* – 7 April 2015 – Although [filmmaker Edgar] Barends just returned from screenings [of his Oscar-nominated documentary ‘Prison Terminal’] at a men’s maximum security prison in San Francisco, and another facility near Sacramento, most of his stops have been in prisons across the Midwest... There were a few where his message was either ridiculed ... or treated less than enthusiastically by the staff. But for the most part ... the film was received with interest... At the Ohio Reformatory for Women, for example, “there was not a dry eye in the house,” which included 80 lifers, as well as prison administrators, said Barends. In February ... after screening the film at Logan Correctional Center near Lincoln, the warden stood next to him in front of the women prison population and “promised” the return of a hospice program that had been scrapped when they were moved from Dwight a couple years ago. According to Barends, of the 1,800 prisons in America, only 70 have hospice programs, and only 20 have prisoner-run programs like

the one in the documentary. Most officials, however, seem open to the idea, and he describes the warm reception he received at a warden’s convention in Iowa City last fall as proof the tide is changing. Officials realize these prisoner-run hospice programs are “not going to break the budget, only that certain rules need to be rewritten,” he added. <http://www.chicagotribune.com/suburbs/auro-ra-beacon-news/news/ct-abn-crosby-documentary-st-0408-20150408-story.html>

#### **Prison Hospice Backgrounder**

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>

### **‘Right to Try’ law won’t grant access to unapproved drugs**

CONNECTICUT | *The Hartford Courant* – 6 April 2015 – Last month, the General Assembly’s Public Health Committee unanimously approved and sent to the House floor a bill that purports to grant terminally ill patients access to medicines and therapies not yet approved by the federal Food & Drug Administration [FDA]. This type of “right to try” legislation has been championed as a quick, merciful end run around the lengthy FDA process for approving new drugs. Thirteen states have already passed such laws. Connecticut should not join them. The proposed bill states that drug manufacturers “may make available” unapproved treatments requested by terminally ill patients. May does not mean must or even should. Sadly, this legislation doesn’t actually help patients who have nothing left to lose. For all the talk about the right to try (more than 20 states have similar legislation pending), these laws do not obligate drug manufacturers to actually do anything. They give patients a right they already have – a right to beg but nothing more. <http://www.courant.com/opinion/op-ed/hc-op-kearns-access-medicine-unapproved-0407-20150406-story.html>

Of related interest:

- TEXAS | *American Statesman* (Austin) – 9 April 2015 – **‘Senate OK’s bill to allow dying patients “right to try” untested drugs.’** A bill to allow terminally ill patients to try experimental medications was unanimously passed by the Senate and now heads to the lower chamber. <http://www.statesman.com/news/news/state-regional-govt-politics/senate-passes-bill-to-allow-dying-patients-right-t/nkqj6/>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- NEVADA | *Las Vegas Review-Journal* – 9 April 2015 – **“Death with dignity” bill dies in Nevada Legislature.** A bill that would allow terminally ill patients to end their life will not be heard in the Nevada Legislature... State Senator Joe Hardy (Republican-Boulder City), chairman of the Senate Committee on Health & Human Services, confirmed he will not schedule the bill for a hearing. Hardy said that as a medical doctor he supports hospice care and helping terminally ill patients manage pain. But he does not support voluntarily ending life, as is allowed in Oregon, Washington and, most recently, Vermont. <http://www.reviewjournal.com/news/nevada-legislature/death-dignity-bill-dies-nevada-legislature>
- RHODE ISLAND | *The Journal* (Providence) – 8 April 2015 – **‘Bill in Rhode Island General Assembly would let terminally ill control own death.’** Should a person facing a terminal illness have the right to hasten their own death? That was the question facing the House Committee on Health, Education & Welfare Wednesday during an emotional debate over what some called “death with dignity” and others called assisted suicide. The bill introduced earlier this year would allow terminally ill patients – those suffering from a disease that would result in death within six months – to have access to a lethal prescription provided that they meet several standards. A doctor would have to determine the patient is capable of making an informed decision. The legislation is modeled on the practices of the handful of states, including Vermont, that allow it. <http://www.providencejournal.com/article/20150408/NEWS/150409326>

## International

### Nine out of ten Korean seniors against life-prolonging treatment

SOUTH KOREA | *The Korea Biz Wire* – 11 April 2015 – According to a survey conducted by the Korea Institute for Health & Social Affairs, only 3.9% of the respondents said that they agreed with having life-prolonging treatment. A whopping 88.9% were opposed to any medical intervention, regardless of their financial situation, who they lived with, their education background, whether they worked or not and their age. Only 2.2% answered they are considering donating their organs, while 0.6% said they have taken classes for seniors to mentally prepare for death. <http://koreabizwire.com/nine-out-of-ten-korean-seniors-against-life-prolonging-treatment/33312>

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**GLOBAL PALLIATIVE CARE NEWS ARCHIVE**

MEDIA WATCH, CREATED AND DISTRIBUTED BY BARRY R. ASHPOLE

Please feel free to share this weekly report with your colleagues.  
Barry R. Ashpole, Guelph, Ontario, CANADA  
519.837.6936 | [barryashpole@bell.net](mailto:barryashpole@bell.net)

**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 cure 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 review of related care gaps and current clinical practices. [read more...](#)

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

## Elder and end-of-life care in Scotland

### **Train prisoners to look after ill inmates, report recommends**

U.K. (Scotland) | Holyrood – 10 April 2015 – Prisoners should get health and social care training in order to help fellow vulnerable inmates. An independent evaluation of high care needs within the Scottish prisoner population recommended prisoners be given responsibility for helping others with daily living activities, such as pushing wheelchairs and cleaning and tidying cells. The Scottish Prison Service [SPS], who commissioned the report, has also been urged to consider training prisoners in a Scottish Qualifications Authority health and social care qualification “with the aim of developing a cohort of health and social care ‘champions.’” Prison officers could be put through the qualification too ... while their own responsibilities for the management of prisoners with severe ill health or disability should be agreed with staff unions. Prison chiefs are now considering the recommendations, which also include holding prisoners with severe ill health or disability in a single specially adapted site, before settling on a way forward. It comes as the prison service braces itself for

an increase in older prisoners... While evaluators were unable to determinate the prevalence of high care needs throughout Scottish prisons due to the absence of a single SPS definition, inmates with disabilities, social care needs and long-term conditions or terminal illness are generally among those who are deemed to fall into the category. <https://www.holyrood.com/articles/news/train-prisoners-look-after-ill-inmates-report-recommends>

#### **Prison Hospice Backgrounder**

The provision – or lack – of quality end-of-life care in the prison system has been highlighted on a fairly regular basis in Media Watch. A compilation of the articles, reports, etc., noted in the weekly report is available on the Palliative Care Community Network website at: <http://www.pcn-e.com/community/pg/file/read/3389844/end-of-life-care-in-prisons>

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

### **End-of-life care for terminally ill “needs major overhaul”**

U.K. (England, Northern Ireland & Wales) | BBC News – 8 April 2015 – The U.K.’s care system for dying patients with terminal illnesses is lacking and needs a major overhaul, says a damning new report.<sup>1</sup> According to London School of Economics researchers, more than 100,000 people a year who would benefit from palliative care are not getting it. Patients are being left without sufficient pain relief and respite. The report found inequalities in access to good care, with certain groups of patients more likely to miss out. With an ageing population and demand for care increasing, the problem looks set to worsen... Those who currently miss out include: the “oldest old” (aged 85+); people living alone; people living in deprived areas; and, black, Asian and ethnic minority groups. Most palliative care goes to cancer patients, even though the diseases account

for less than a third of deaths. Only a fifth of new referrals to specialist end-of-life care are for people with non-cancer diagnoses. <http://www.bbc.com/news/health-32201594>

#### **Extract from BBC report**

The net potential savings [of providing palliative care] are more than £30 million in England, at least £2 million in Wales, more than £1 million in Northern Ireland, and more than £4 million in Scotland.

#### **Specialist Publications**

‘Only half of clinicians feel patients’ end of life needs are met’ (p.11), in *OnMedica*.

Cont.

1. 'Equity in the provision of palliative and end of life care in the U.K.: Review,' Personal Social Services Research Unit, London School of Economics & Political Science, April 2015. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>

Of related interest:

- U.K. (England) | *The Lancashire Evening Post* (Preston) – 10 April 2015 – **'Hospice's end of life service "at risk."** St. Catherine's Hospice ... receives the equivalent of £400,000 less funding each year compared to the national average, and says its vital team of community clinical nurse specialists could be forced to fold if the gap isn't closed. Chief executive Stephen Greenhalgh was responding to the publication of research from Marie Curie, which highlights the needs of terminally ill people that are not being met because of insufficient funding. St. Catherine's receives 26% of its annual £5 million running costs from the National Health Service – the equivalent of £1.3 million – whereas the national average is 34%. It means the hospice is losing out on approximately £400,000 each year. <http://www.lep.co.uk/news/hospice-s-end-of-life-service-at-risk-1-7202874>

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

#### **Changes in perceptions of opioids before and after admission to palliative care units in Japan: Results of a nationwide bereaved family member survey**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 9 April 2015 – Many bereaved family members [i.e., study participants] had misconceptions of opioids before admission. There was improvement after bereavement, but understanding remained low. Respondents less than 65 years old showed significantly greater decreases in misconceptions ... compared to older generations, after bereavement. Bereaved family members who were misinformed about opioids by physicians were significantly more likely to have misconceptions... Educational interventions for physicians are needed to ensure that they offer correct information to the general population. <http://ajh.sagepub.com/content/early/2015/04/09/1049909115579407.abstract>

#### **Is there a need for early palliative care in patients with life-limiting illnesses? Interview study with patients about experienced care needs from diagnosis onward**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 7 April 2015 –The early integration of specialist palliative care has been shown to benefit the quality of life of patients with advanced cancer. In order to explore whether other seriously ill people and people at even earlier phases would also benefit from early palliative care, the authors conducted 18 qualitative interviews with people having cancer, chronic obstructive lung disease, heart failure, or dementia at different phases of the illness trajectory about how they experienced care needs related to their disease from diagnosis onward. Respondents experienced needs within the different domains of palliative care at different stages of the illness and different illness types or duration of the illness. <http://ajh.sagepub.com/content/early/2015/03/31/1049909115577352.abstract>

Noted in Media Watch, 30 March 2015, #403 (p.16):

- *HEMONC TODAY* | Online – 25 March 2015 – **'Palliative medicine under the microscope: Not every patient with cancer needs palliative care.'** It would be extremely hard to question the benefits of palliation for patients with intractable disease. At a community level, a litany of studies have shown conclusively active treatment is an expensive option that affords little benefit ... to the dying patient, and is effectively and appropriately replaced by timely referral for palliative and then hospice care. That said, the thought all patients with cancer should receive palliative care ... just doesn't make sense to me as clinician with 40 years of experience. <http://www.healio.com/hematology-oncology/palliative-care/news/print/hemonc-today/%7B6e166b0e-604b-47a1-ae4-6ed28bc5bf4%7D/palliative-medicine-under-the-microscope-not-every-patient-with-cancer-needs-palliative-care>



## Moving to high-value care: More thoughtful use of cardiopulmonary resuscitation

*ANNALS OF INTERNAL MEDICINE* | Online – 7 April 2015 – In hospitals, physicians perform cardiopulmonary resuscitation (CPR) in hospitals repeatedly and reflexively. Too often CPR occurs regardless of prognosis, without knowing whether the patient desires CPR, and knowing that we may do harm. In this commentary, leaders of the European Federation of Internal Medicine and American College of Physicians remind physicians of the importance of discussing patient preferences for CPR and individual patient prognosis after CPR with hospitalized patients. <http://annals.org/article.aspx?articleid=2240199>

Of related interest:

- *JAMA INTERNAL MEDICINE* | Online – 6 April 2015 – ‘**Influence of institutional culture and policies on do-not-resuscitate decision making at the end of life.**’ Institutional cultures and policies might influence how physician trainees develop their professional attitudes toward autonomy and their willingness to make recommendations regarding the decision to implement a DNR order. A singular focus on autonomy might inadvertently undermine patient care by depriving patients and surrogates of the professional guidance needed... <http://archinte.jamanetwork.com/article.aspx?articleid=2212265>
- *JOURNAL OF HOSPICE & PALLIATIVE NURSING*, 2015;17(2):128-132. ‘**Cultural differences in discussion of do-not-resuscitate status and hospice.**’ Previous research has shown African American and Latino populations prefer more aggressive care at end of life. Prior to consultation, there were statistically significant differences regarding DNR status; after consultation, there were no differences in acceptance of DNR among races. The authors conclude that palliative care consultations make a significant difference in this patient population. [http://journals.lww.com/jhpn/Fulltext/2015/04000/Cultural\\_Differences\\_in\\_Discussion\\_of.10.aspx](http://journals.lww.com/jhpn/Fulltext/2015/04000/Cultural_Differences_in_Discussion_of.10.aspx)

## A culture of avoidance: Voices from inside ethically difficult clinical situations

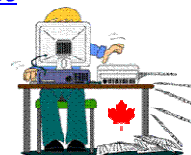
*CLINICAL JOURNAL OF ONCOLOGY NURSING*, 2015;19(2):159-165. The authors found that many healthcare providers remain silent about ethical concerns until a precipitating crisis occurs and ethical questions can no longer be avoided. Patients, families, nurses, and physicians tended to delay or defer conversations about prognosis and end-of-life treatment options. Individual, interactional, and system-level factors perpetuated the culture of avoidance. These included the intellectual and emotional toll of addressing ethics, differences in moral perspectives, fear of harming relationships, lack of continuity in care, emphasis on efficiency, and lack of shared decision making. <http://europepmc.org/abstract/med/25840381>

Of related interest:

- *ETHICS & SOCIAL WELFARE* | Online – 2 April 2015 – ‘**Structuring bioethics education: The question, the disciplines, and the integrative challenge.**’ This paper introduces ... a particular approach to the structuring of courses of bioethics education, an approach that has the merits of being both relevant to a wider non-professional audience and readily applicable to the circumstances in which ordinary people are called upon to make bioethical decisions. <http://www.tandfonline.com/doi/full/10.1080/17496535.2015.1005555#.VSbwYGdzaos>

### 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>



### **Assessing best interests in end-of-life care for a patient in a minimally conscious state**

*END OF LIFE JOURNAL* | Online – Accessed 10 April 2015 – The legal basis and principles for the lawful withholding of life-sustaining treatment from people in a minimally conscious state have been laid out in the Supreme Court judgment in *Aintree University Hospitals National Health Service Foundation Trust (Respondent) vs. James (Appellant)* [2013]. This was the first case under the Mental Capacity Act 2005 to come before the Supreme Court and hence it is of legal importance. The case involved a 68-year-old man who had multiple physical co-morbidities and who was diagnosed as being in a minimally conscious state. This article discusses the case and the approach taken by the Court of Protection and the Court of Appeal in applying the Mental Capacity Act 2005 when assessing whether withholding life-sustaining treatment is ever in a person's best interests. <http://eolj.bmj.com/content/5/1/e900003.abstract>

### **Preferred place of death: Determining factors and the role of advance care planning**

*END OF LIFE JOURNAL* | Online – Accessed 10 April 2015 – One of the many factors associated with a good death is when patients have been able to be cared for, and have died, in their preferred place. Supporting patients to die in their preferred place of care is considered a quality indicator of palliative and end-of-life care. Most people wish to die within their usual place of residence. However, the majority of people die in an acute hospital environment. There are various factors that influence where people die, including the person's diagnosis, functional status, social situation, level of support of family caregivers, and the availability of good end-of-life care services. The implementation of advance care planning discussions has also been associated with an increased likelihood of terminally ill patients dying in their preferred place. This article will discuss some of the factors that determine whether people will die in the home setting, and then provide an overview of advance care planning and how it can influence place of death and improve the quality of life of dying patients. <http://eolj.bmj.com/content/5/1/e900004.abstract>

### **Older people living alone at home with terminal cancer**

*EUROPEAN JOURNAL OF CANCER CARE* | Online – 7 April 2015 – This study describes the lived experiences of older people coping with terminal cancer and living alone, focusing on how they face challenges of the biographical life changes from their disease progression. four main themes emerged: 1) biographical disruption: adjusting to change; 2) biographical continuity: preserving normality; 3) biographical reconstruction: redefining normality; and, 4) biographical closure: facing the end. Biographical disruption was a suitable framework for analysis, permitting identification of the biographical disruptions of the individual's world and the reframing that is undertaken by the individual to maintain autonomy and independence while acknowledging and accepting their closeness to death. Understanding the factors associated with the individual's need to maintain their own identity will enable nurses working with this population to tailor support plans that meet the individuals' needs while maintaining or restoring the person's sense of self. Interventions that directly address end-of-life suffering and bolster sense of dignity and personhood need to be considered. <http://onlinelibrary.wiley.com/doi/10.1111/ecc.12314/abstract>

### **Palliative care tailored towards the needs of the poor in India**

*INDIAN JOURNAL OF SURGICAL ONCOLOGY* | Online – 7 April 2015 – Traditional approaches to palliative care may not meet the unique needs of poor cancer patients in developing countries. Cancer patients treated in India are often unable to make repeat visits to the hospital, pay for drugs, or understand and follow complex treatments. Many are from rural areas and may lack basic financial or social support. The authors' palliative care clinic has taken a series of innovative first steps towards meeting these unique needs, from providing treatment without complete diagnosis, accelerating through the World Health Organization analgesic schedule, systematically simplifying prescriptions, and providing treatment free of charge. This paper describes these first steps, presents an initial evaluation of their impacts, and articulates a number of opportunities for additional improvements. <http://link.springer.com/article/10.1007/s13193-015-0409-9>



## **Barriers to goals of care discussions with seriously ill hospitalized patients and their families: A multicenter survey of clinicians**

*JAMA INTERNAL MEDICINE*, 2015;175(4):549-556. Seriously ill hospitalized patients have identified communication and decision making about goals of care as high priorities for quality improvement in end-of-life care. Interventions to improve care are more likely to succeed if tailored to existing barriers. The following family member-related and patient-related factors were consistently identified ... as the most important barriers to goals of care discussions: 1) family members' or patients' difficulty accepting a poor prognosis; 2) family members' or patients' difficulty understanding the limitations and complications of life-sustaining treatments; 3) disagreement among family members about goals of care; and, 4) patients' incapacity to make goals of care decisions. Clinicians perceived their own skills and system factors as less important barriers. Participants viewed it as acceptable for all clinician groups to engage in goals of care discussions – including a role for advance practice nurses, nurses, and social workers to initiate goals of care discussions and be a decision coach. <http://archinte.jamanetwork.com/article.aspx?articleid=2107609>

Of related interest:

- *INTERNATIONAL JOURNAL OF PALLIATIVE CARE* | Accessed 10 April 2015 – **Concordance between experiences of bereaved relatives, physicians, and nurses with hospital end-of-life care: Everyone has their “own truth.”** Relatives, physicians, and nurses [i.e., study participants] had different perspectives on the quality of the final days of patients' lives, on their quality of dying, and on communication about impending death. Everyone seems to experience his/her “own truth.” To achieve improvements in care in the dying phase, more emphasis should be put on the collaboration between health care professionals and relatives in the therapeutic alliance with patients. Furthermore, physicians should be more willing to timely discuss a poor prognosis and to check whether the patient and relative's understanding align with physicians'. <http://www.hindawi.com/journals/ijpc/2015/623890/>

Cont. next page

### **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.

### **Distribution**

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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.

- *JOURNAL OF MEDICINE AND THE PERSON* | Online – 31 March 2015 – ‘**The meaning of everything: Communication at the end of life.**’ Communication about end-of-life care is increasingly recognized as a core clinical skill, but doctors are often unprepared to have these conversations. Crisis situations at the end of life, such as when a hospitalized patient with a poor prognosis requests that “everything” be done, pose even greater communicative challenges. Such decisions are often regarded as a demand for care that may be burdensome or even harmful, rather than the start of an important conversation about values and goals. Current models of communication are less about accurate transmission of information and more about the ways in which communication constitutes our social world. Thus, the goal of communication training for physicians should be less about tools and scripts, and more about doctors learning to engage patients in conversation. The authors suggest strategies for promoting dialogue to more effectively explore the concerns and misunderstandings that might underlie decisions to “do everything.” <http://link.springer.com/article/10.1007/s12682-015-0205-x#>
- *TRENDS IN CARDIOVASCULAR MEDICINE* | Online – 3 April 2015 – ‘**How to discuss goals of care with patients.**’ While clinicians receive extensive training on how to identify and treat illness, communication techniques, especially those centering around emotion-laden topics such as end-of-life care, receive short shrift medical education. Fortunately, communication techniques can be taught and learned through deliberate practice and in this article, the authors seek to discuss a framework, drawn from published literature and their own experience, for approaching goals of care discussions in patients with cardiovascular disease. [http://www.tcmonline.org/article/S1050-1738\(15\)00115-2/abstract?cc=y](http://www.tcmonline.org/article/S1050-1738(15)00115-2/abstract?cc=y)

### Hospice care for children with cancer: Where do these children die?

*JOURNAL OF PEDIATRIC HEMATOLOGY/ONCOLOGY* | Online – 12 April 2015 – Many children who die of cancer enrol in hospice programs. How frequently such children remain in hospice to die at home, or disembark from hospice and die in the hospital, has not been described. A child’s location of death has important implications for quality of life and parental adaptation. This [article] represents a sub-analysis of a retrospective study of 202 consecutive oncology patients who died at a single center between 1 January 2006 and 31 December 2010. Of 95 children who enrolled in hospice, 82 had known location of death. Sixty (73%) died at home or an inpatient hospice unit, 15 (18%) died in the oncology unit, 5 (6%) died in the intensive care unit, and 2 (2%) died in the emergency department. The median length of hospice services was 41 days, twice the national median of 21 days reported in adults. One quarter of children disenrolled from hospice care, ultimately dying in an acute care setting. [http://journals.lww.com/jpho-online/Abstract/publishahead/Hospice\\_Care\\_for\\_Children\\_With\\_Cancer\\_Where\\_Do.98700.aspx](http://journals.lww.com/jpho-online/Abstract/publishahead/Hospice_Care_for_Children_With_Cancer_Where_Do.98700.aspx)

Of related interest:

- *ARCHIVES DE PEDIATRIE* | Online – Accessed 12 April 2015 – ‘Development, implementation, and analysis of a “collaborative decision-making for reasonable care” document in pediatric palliative care.’ In France, a legal framework and guidelines state that decisions to limit treatments require a collaborative decision meeting and a transcription of decisions in the patient’s file. The do-not-attempt-resuscitation order involves the same decision-making process for children in palliative care. To fulfill the law’s requirements and encourage communication within the teams, the Resource Team in Pediatric Palliative Care in Aquitaine created a document shared by all children’s hospital units, tracing the decision-making process. This study analyzed the decision-making process, quality of information transmission, and most particularly the relevance of this new “collaborative decision-making for reasonable care” card. <http://europepmc.org/abstract/med/25840464>

**N.B.** French language article.

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

### **Only half of clinicians feel patients' end of life needs are met**

*ONMEDICA* | Online – 8 April 2015 – A survey commissioned by Marie Curie, the charity for people living with terminal illnesses, of 500 clinical professionals across the U.K. (including GPs) showed that the profession was worried about the quality of care and fair access. The new Ipsos MORI online survey ... looked at the standards and quality of care that they encountered for people with terminal illnesses. Almost half (47%) of respondents did not agree that the needs of patients were adequately met overall, and far fewer said the same was true for those using out-of-hours social care (15%) or in A&E [Accident & Emergency] (15%). Only a third of respondents (31%) said that out-of-hours medical care met peoples' needs adequately, while 45% agreed the same was true for hospital in-patients. A larger proportion said that people receiving care in their own homes or in hospices had their needs met – 53% and 91% respectively – agreed that those needs were adequately met. When asked which issues were a barrier to meeting the needs of terminally ill people, around two thirds (65%) of clinicians said lack of coordination between teams delivering care, 65% said insufficient funding for services, and 67% cited time and poor staff. <http://www.onmedica.com/NewsArticle.aspx?id=a1288f14-a1dd-49ac-9b3d-ff424ce7c418>

### **Brain death: The European perspective**

*SEMINARS IN NEUROLOGY*, 2015;35(2):139-144. There is a general consensus on both the medical concept of brain death in Europe as well as the minimum fundamental clinical standards that are required for its diagnosis-the absence of consciousness, brainstem reflexes, and the ability to breathe in the absence of reversible or confounding conditions. Two aspects of brain death determination are addressed in this article. The authors analyze how brain death is diagnosed across Europe, identifying both the similarities and differences that exist between countries... In addition, they describe the very considerable variations in when brain death determinations are made between and within individual European countries, and propose that they are due to differences in the end-of-life care practices in patients with irreversible brain injuries, medical attitudes, and organ donation practices. Although legislation is available to standardize the brain death diagnosis process in most individual European countries, there are still disparities across Europe as a whole. The current variation in practice makes a continental consensus for the definition of brain death imperative. <https://www.thieme-connect.de/DOI/DOI?10.1055/s-0035-1547533>

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## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2015/04/media-watch/#lived>

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](http://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>