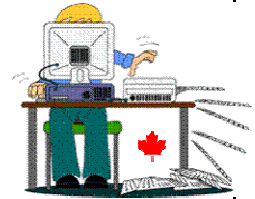


## Media Watch...

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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Compilation of Media Watch 2008, 2009, 2010, 2011, 2012, 2013, 2014 ©

Compiled & Annotated by Barry R. Ashpole

Approaching the end-of-life: Scroll down to [Specialist Publications](#) and 'Negotiating futility, managing emotions: Nursing the transition to palliative care' (p.14), in *Quality Health Research*.

## Canada

### Ontario Consent & Capacity Board

#### Stalemate: Deciding life or death

ONTARIO | *The Toronto Star* – 28 September 2014 – The little-known Consent & Capacity Board (CCB) – the only one of its kind in North America, perhaps anywhere – is a working laboratory for the most pressing issue facing Canada's healthcare system: the end of life. When a physician's treatment proposal is challenged by a family member whose loved one can no longer communicate their wishes, doctors can make an application to the CCB. The Board then convenes a hearing within seven days ... headed by a lawyer, a public member and a medical professional, typically a psychiatrist. It must ultimately determine an incapacitated patient's "prior wishes" or "best interests." The panel must then issue a binding order within 24 hours of the hearing's conclusion – a remarkably fast and economical process relative to the courts. A *Toronto Star*/Ryerson University analysis of all 45 published end-of-life decisions issued by the board over the past 12 years reveals decisions that have trumped family wishes, overturned physicians' medical recommendations, decided how and when people die and controlled their most precious final moments. In more than three quarters of the cases, pa-

tients had not clearly communicated their wishes for treatment at the end of life. Deciphering end-of-life wishes without clear directives left doctors, families and CCB tribunal members asking: What would they have wanted? What was in their best interest? Of the 45 cases, the vast majority ... happened in hospitals... Of those hospital-based hearings, intensive care units were the setting of the dispute about 60% of the time. The CCB sided with physicians in 84% of the hearings involving disputes with patient family members. [http://www.thestar.com/news/world/2014/09/26/stalemate\\_deciding\\_life\\_or\\_death.html](http://www.thestar.com/news/world/2014/09/26/stalemate_deciding_life_or_death.html)

#### Extract for *The Toronto Star* report

Skepticism and distrust are shared by many physicians interviewed who say the board ignores medical standards of care and should have more clinical physicians represented on the panels. But Canada's highest court and leading health policy experts hail the CCB model as a leader in North America, providing a swift and balanced alternative to the courts.

## Elder care

### **Editorial: Homecare in Quebec is profoundly inadequate**

QUEBEC | *The Montreal Gazette* – 23 September 2014 – The office of Quebec's ombudsman delivered another damning report last week, painting a dire portrait of health and social services, especially for seniors.<sup>1</sup> And not for the first time, Quebec's homecare strategy was singled out among the services all too often failing patients. Among the disturbing findings of the ombudsman's report were regional disparities, lengthy waits for service even after need was determined, and levels of care being influenced by the presence of family members or the patients' perceived resources. Add to this a lack of quality control, widely diverging standards, insufficient evaluations – and in some cases a lack of time actually spent in patients' homes by personnel – uncovered by Quebec's auditor general in 2013. The latest ombudsman's report cites some dreadful examples. <http://www.montrealgazette.com/Editorial+Homecare+Quebec+profoundly+inadequate/10228579/story.html>

1. 'Rapport annuel 2013-2014 du Protecteur du citoyen – Faits saillants concernant le réseau de la santé et des services sociaux,' <http://www.protecteurducitoyen.qc.ca/dossiers-et-documentation/rapports-annuels/>

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

Representative sample of recent news media coverage:

- iPOLITICS | Online – 22 September 2014 – '**Supreme Court weighs assisted suicide question amid watershed fall session.**' The Supreme Court of Canada will start its fall sitting with a bang as it hears a case in mid-October that could change the lives of Canadians – whether physician-assisted suicide should be allowed for gravely ill people facing inevitable death. The current assisted-death hearing is, in a sense, a re-do of the Sue Rodriguez [case] ... <http://www.ipolitics.ca/2014/09/22/supreme-court-headed-for-another-potentially-nation-changing-session/>
- BRITISH COLUMBIA | *The Times-Colonist* (Vancouver) – 20 September 2014 – '**Comment: 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>

## U.S.A.

### **Training in hospice and palliative care a "huge need"**

MICHIGAN | *Grand Rapids Business Journal* – 26 September 2014 – There has already been a tremendous amount of attention given to the looming doctor and nursing shortage, and hospice and palliative care are already behind when it comes to the number of caregivers in the profession. That is, in part, because hospice and palliative care are relatively new fields. The first hospice program opened in 1974, and hospice and palliative medicine only became an approved subspecialty by the American Board of Medical Specialties in 2006. The Center for Palliative Care said, in 2010, there were only 73 accredited allopathic subspecialty training fellowship programs in the U.S. Collectively, those programs were producing approximately 86 new palliative medicine physicians per year. <http://www.grbj.com/articles/80666-training-in-hospice-and-palliative-care-a-huge-need>

Cont.

Noted in Media Watch, 16 July 2012, #262 (p.10):

- **HEALTH LEADERS** | Online – 13 July 2012 – '**Palliative care challenged by physician shortage.**' While there is about one cardiologist for every 71 people experiencing a heart attack and one oncologist for every 141 newly diagnosed cancer patients, there is only one palliative care physician for every 1,200 people living with a serious or life-threatening illness.<sup>1</sup> <http://www.healthleadersmedia.com/content/MAG-282158/Palliative-Care-Challenged-by-Physician-Shortage>

1. 'Estimate of current hospice and palliative medicine physician workforce shortage,' *Journal of Pain & Symptom Management*, 2012;40(6):899-911 [Noted in Media Watch, 13 December 2010, #179 (p.9)] [http://www.jpmsjournal.com/article/S0885-3924\(10\)00602-0/abstract](http://www.jpmsjournal.com/article/S0885-3924(10)00602-0/abstract)

### **A whole new system of oversight is needed for elder care**

*THE NEW YORK TIMES* | Online – 25 September 2014 – We need a system of local MediCaring ElderCare Community Boards that would monitor the well-being of the frail elderly, measure the cost of their care and optimize the supply and quality of services. These would oversee not only medical care, but also the needed supportive services like adapted housing, disability transportation, in-home nutrition and support for family caregivers. This approach would ensure that services match the needs of a community's frail elder population, through planning and oversight. In addition, each frail elderly person and family would develop comprehensive care plans with their care team, which would consist of their key service providers. The care plan would address how and where the elderly person would live, who would help them, what goals mattered to the person and family, and all the rest of what makes it possible to live well in the shadow of progressive disability and eventual death. Physicians and health systems would be required to routinely assess each frail elderly patient's situation comprehensively to craft the care plans, including instruction about preferences for urgent care. <http://www.nytimes.com/roomfordebate/2014/09/25/finding-humane-care-at-the-end-of-life/a-whole-new-system-of-oversight-is-needed-for-elder-care>

Of related interest:

- *THE NEW YORK TIMES* | Online – 26 September 2014 – '**Profits place treatment over humane care for elderly.**' Despite advances in palliative care, intensive care admissions and repeat hospitalizations have risen, because of the system's financial incentives. <http://www.nytimes.com/roomfordebate/2014/09/25/finding-humane-care-at-the-end-of-life/profits-place-treatment-over-humane-care-for-elderly>
- *THE NEW YORK TIMES* | Online – 25 September 2014 – '**Finding humane care at the end of life.**' Many Americans will end their lives in surroundings that only add to their misery. Those who hoped to die in their own beds are often forced into nursing homes, some of which mistreat patients. Even if home care is arranged, it too can be substandard, even abusive. And those who hope for government guidance can find unreliable information. What can be done to ensure that the elderly get the care they want and need, particularly in their dying days? <http://www.nytimes.com/roomfordebate/2014/09/25/finding-humane-care-at-the-end-of-life?hp&action=click&pgtype=Homepage&module=c-column-top-span-region&region=c-column-top-span-region&WT.nav=c-column-top-span-region>

### **[Media Watch Online](#)**

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

## The return of death panels? Government-funded end-of-life planning is morally questionable

*FORBES* | Online – 24 September 2014 – End-of-life planning is back on the radar screen because of a very thorough report just released report by the Institute of Medicine...<sup>1</sup> It comprises a wealth of information on the state of end-of-life planning in America today. Unfortunately, it contains a dangerous recommendation: government-funded counselling. At its best, end-of-life counselling would ensure that patients are well informed about the costs and benefits of intense medical intervention at the end of life. Although dissatisfied with where we stand today, the report notes progress: In the last two decades, palliative and hospice care has grown tremendously. By 2011, a majority of hospitals had palliative-care pro-

grams. Almost half of adults over 40 have an advanced-planning directive and have discussed care preferences with a loved one. <http://www.forbes.com/sites/theapothecary/2014/09/24/the-return-of-death-panels-government-funded-end-of-life-planning-is-morally-questionable/>

### Specialist Publications

**'In a longevity society, loss and grief are emerging risk factors for health care use: Findings from the Health & Retirement Survey Cohort Aged 50 to 70 Years'** (p.7), in *American Journal of Hospice & Palliative Medicine*.

1. 'Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,' Institute of Medicine, September 2014. [Noted in Media Watch, 22 September 2014, #376 (p.4)] <http://www.iom.edu/~media/Files/Report%20Files/2014/EOL/Report%20Brief.pdf>

## How to die in America: Welcome to La Crosse, Wisconsin

WISCONSIN | *Forbes* – 23 September 2014 – One of the most intractable and politically charged problems in the U.S. healthcare system is end-of-life care. Unlike other third rail issues it only took two words – death panels – to put a screeching halt to the much needed public conversation about how we address medical care during the last six to twelve months of life. While she not only managed to remove the payment provisions for end-of-life consultation from Obama-care, Sarah Palin's quip ... also put the final nail in the coffin and public debate was DOA. Unfortunately that didn't alter the immutable facts about end-of-life management. It is projected that total U.S. health care expenditures will reach \$5 trillion by 2022 from its current level of \$3 trillion. A disproportionately large percentage of total national health care expenditures, roughly 2 to 1, occurs during the last twelve months of life with nearly 30% of all Medicare spending is incurred during the last six months of a patient's life. The extrapolations for end-of-life care in the future are truly sobering. We all

know there are no silver bullets when it comes to healthcare, but one promising opportunity to dramatically improve the "tenor of care" during the inescapable end-of-life process for all Americans is the use of a legal form known as an "advance directive." <http://www.forbes.com/sites/offwhitepapers/2014/09/23/how-to-die-in-america-welcome-to-la-crosse/>

### **Extract from *Forbes* article**

Imagine a town of 50,000 Americans where 96% of those who die have signed an "advance directive" codifying their conscious decision about how they would like to die. This is quite an accomplishment given we haven't been able to move the needle at a national level beyond 30% over the past 30 years. By definition every possible polarized constituency in this town – conservative and liberal, religious and secular, republican and democrat, rich and poor – agree on one of the most divisive political and social issues in America.

Cont.

Noted in Media Watch, 10 March 2014, #348 (p.2):

- WISCONSIN | National Public Radio – 5 March 2014 – **'The town where everyone talks about death.'** In this community [of La Crosse], talking about death is a comfortable conversation – neighbors gossip about who on the block hasn't filled out their advance directive. <http://www.npr.org/blogs/money/2014/03/05/286126451/living-wills-are-the-talk-of-the-town-in-la-crosse-wis>

Of related interest:

- FLORIDA | *The News Herald* (Panama City) – 22 September 2014 – **'Our view: End-of-life debate.'** Determining a patient's wishes for end-of-life care is one of the most challenging issues in medicine. Too few people discuss or complete advance directives while they still have the mental and physical capacity to do so. Then if illness strikes, medical staffs and loved ones are forced to make crucial decisions for patients, without their guidance. That is a recipe for heartache, family dissension, and questionable medical interventions. Many Americans are aware of these potential nightmares, yet they continue to avoid the task of filling out the directives. <http://www.newsherald.com/opinions/editorials/our-view-end-of-life-debate-1.376387>

## International

### End-of-life care in England

#### ***Exploring the cost of care at the end of life***

U.K. (England) | The Nuffield Trust – 26 September 2014 – The research also explores whether reduced hospital activity and costs at the end of life were likely to be offset by increased care costs in other health and social care settings using the Marie Curie home-based palliative care nursing service – the subject of a previous study by the Nuffield Trust.<sup>1</sup> The results suggest that cost savings might be available if community-based support were made more widely available to help people to die in their own homes, where that was their preference. Given the finite resources available for health care, it is important that there is an understanding of the costs of end-of-life care. However, acquiring good-quality data surrounding costs for palliative care is challenging, especially as care services for those at the end of life are fragmented across many different providers. "This work demonstrates how crucial it is that we develop better ways to understand resource use in everyday care. This would help care services to be responsive to the needs of those near to

death, so they can provide support and care in the most appropriate setting for the individual." Theo Georghiou, Senior Research Analyst, Nuffield Trust and report author. [http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end\\_of\\_life\\_care.pdf](http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/end_of_life_care.pdf)

#### **Extract from Nuffield Trust report**

A key message of this work is that it is essential that we develop better ways to understand resource use in everyday care. National Health Service England's palliative care funding projects are an important manifestation of this aim with respect to end-of-life care.

#### **Specialist Publications**

**'Supporting family carers providing end-of-life home care: A qualitative study on the impact of a hospice at home service'** (p.11), in *Journal of Clinical Nursing*.

1. 'The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life,' Patterns of Care at the End-of-Life Project, Nuffield Trust, November 2012. [Noted in Media Watch, 19 November 2012, #280 (p.7)] <http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing>

## ***Palliative care services in Australia 2014***

AUSTRALIA | Australian Institute of Health & Welfare – 24 September 2014 – 'Palliative care services in Australia 2014' is the third in a planned series of annual reports providing a detailed picture of the national response to the palliative care needs of Australians. Information from a range of data sources from 2012-2013 and, where indicated 2011-2012, are presented, as are changes over time. <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548892>

### **Specialist Publications**

**'Palliative Care Phase: Inter-rater reliability and acceptability in a national study'** (p.14), in *Palliative Medicine*.

## **European Union health ministers to promote palliative care, pain therapy**

ITALY | *New Europe* – 24 September 2014 – The European Union (EU) health ministers pledged to further promote the use of palliative care and pain therapy in the EU member states during a two-day informal meeting that concluded in Milan on Tuesday. The ministers reached a common position on the need to create a "network" ensuring training of professionals and exchange of information, Italian Health Minister Beatrice Lorenzin, who chaired the meeting on behalf of the current EU rotating president Italy, told a press conference. Italy was the first country in Europe to adopt a law in 2010 which defines pain therapy as a set of diagnostic and therapeutic initiatives intended to control and suppress moderate to severe chronic pain, she noted. "The necessity to develop domestic assistance networks to assure patients the possibility to remain at home until the end of their life is undeniable," Lorenzin pointed out. Presently, there are 221 hospices providing a total of 2,307 beds in Italy, she said, highlighting the importance of this philosophy of care centered on the needs, including the emotional ones, of chronically or terminally ill patients. <http://www.neurope.eu/article/eu-health-ministers-promote-palliative-care-pain-therapy>



Of related interest:

- IRELAND | *The Independent* (Dublin) – 22 September 2014 – **'Time for a real conversation about looking after our elderly.'** According to a European Union-funded survey of 28 member states, only Cypriot adults are less likely than we are to have a discussion with friends or family about future care. We just don't seem able to sit down with the next generation and thrash this out. It's a conversation we need to have more often across kitchen tables up and down the land because our population is ageing much more quickly than many others in Europe, thanks to our declining birth rate and better health care. While Ireland has one of the lowest proportions of people aged over 65s, this is changing rapidly. Between 2006 and 2011 the population grew by 8.2%, while the percentage over 85 expanded 25%. <http://www.independent.ie/opinion/time-for-a-real-conversation-about-looking-after-our-elderly-30602948.html>

### **Barry R. Ashpole**

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





## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- SWITZERLAND | *The Washington Post* (U.S.) – 22 September 2014 – '**Tourism to Switzerland for assisted suicide is growing, often for nonfatal diseases.**' An ongoing study of assisted suicide in the Zurich area has found the number of foreign people coming to the country for the purpose is rising.<sup>1</sup> For example, 123 people came in 2008 and 172 in 2012. 611 people came over that period from 31 countries, mostly from Germany and Britain: 44% and 21% of the total, respectively. Twenty-one people came from the U.S. The study found the median age for what it termed "suicide tourism" was 69 years, and just under 60% were women. [http://www.washingtonpost.com/national/health-science/tourism-to-switzerland-for-assisted-suicide-is-growing-often-for-nonfatal-diseases/2014/09/22/3b9de644-2a14-11e4-958c-268a320a60ce\\_story.html](http://www.washingtonpost.com/national/health-science/tourism-to-switzerland-for-assisted-suicide-is-growing-often-for-nonfatal-diseases/2014/09/22/3b9de644-2a14-11e4-958c-268a320a60ce_story.html)
- 1. 'Suicide tourism: A pilot study on the Swiss phenomenon,' *Journal of Medical Ethics*, 20 August 2014. [Noted in *Media Watch*, 25 August 2014, #372 (p.2)] [http://jme.bmj.com/content/early/2014/07/03/medethics-2014-102091.short?q=w\\_jme\\_ahead\\_tab](http://jme.bmj.com/content/early/2014/07/03/medethics-2014-102091.short?q=w_jme_ahead_tab)
- INDIA | *The Assam Tribune* (Guwahati) – 21 September 2014 – '**State Government misses deadline on Supreme Court's mercy killing opinion.**' The Assam government has missed the Supreme Court deadline that had sought its response on the validity of "mercy killing" or euthanasia. The apex court had set a deadline of eight weeks (two months) on 16 July [2014] asking all the States and Union Territories to respond on the viability and validity of euthanasia (mercy killing)... <http://www.assamtribune.com/scripts/detailsnew.asp?id=sep2214/at051>

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

### **In a longevity society, loss and grief are emerging risk factors for health care use: Findings from the Health & Retirement Survey Cohort Aged 50 to 70 Years**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 25 September 2014 – In a society of long lives, parent and child life can overlap by as much as 50 years. Most children now experience the death of their parents as adults. Many of the 2.5 million deaths each year in the U.S. are parents. Parental loss is a risk factor for subsequent illness. The ... survey is a representative cohort of persons aged 50 to 70 years. Using the 2010 cohort data, the authors estimate risk for use of health care after the death of a parent. Loss is a near universal experience in the cohort (87%). A report of any loss increases risk of health care utilization by 20% to 30%. For a longevity society, preventing loss-related hospitalization is a measurable outcome for bereavement care. <http://ajh.sagepub.com/content/early/2014/09/24/1049909114552125.abstract>

### **Hospice attitudes of physicians and nurses: A pilot study**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 24 September 2014 – The purpose of this study was to gauge the attitudes of internal medicine (IM) physicians and hospice nurses on the hospice programs in a Southeastern U.S. county. A postal survey sought views on the following issues: 1) the level of control that hospice affords dying patients; 2) health care professionals' education and communication involving the dying process; 3) the hospice referral process; 4) characteristics of a "good death"; and, 5) gender versus professional role regarding hospice attitudes. The data revealed that occupational role in hospice care has a more significant function in the development of cognitive attitudes than of gender regarding hospice programs and that professional education needs more emphasis on the study of end-of-life issues, as well as open communication between health care professionals and patients during the dying process. Physicians were less likely than nurses to agree that patient control was important. Additionally, what constitutes a good death was similar to previous studies. <http://ajh.sagepub.com/content/early/2014/09/23/1049909114552124.abstract>

## **The Stanford Prison Experiment: Implications for the care of the "difficult" patient**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online – 23 September 2014 – Approximately 15% of patients are perceived by clinicians as "difficult." Early theories about difficult patients focused on patients' and clinicians' characteristics, often underemphasizing the influence of the environment on patients' behavior. The Stanford Prison Experiment, a classic experiment in the psychology of human behavior, provides a broader systems approach for understanding the environmental influences on patient behavior. A systems approach to the care of the difficult patient takes into consideration not only the patient's characteristics but also the health care environment and the more distal environments (i.e., familial, societal, and cultural). Clinicians who are aware of the multilevel impact of these various environments on the behavior of patients are better equipped to understand, address, and hopefully even prevent difficult patient encounters. <http://ajh.sagepub.com/content/early/2014/09/22/1049909114552126.abstract>

### **Palliative care and emergency medicine**

#### **End of life/palliative care/ethics**

*EMERGENCY MEDICINE CLINICS OF NORTH AMERICA* | Online – 16 September 2014 – Palliative and end-of-life care, once the purview of oncologists and intensivists, has also become the responsibility of the emergency physician. As our population ages and medical technology enables increased longevity, it is essential that all medical professionals know how to help patients negotiate the balance between quantity and quality of life. Emergency physicians have the opportunity to educate patients and their loved ones on how to best accomplish their goals of care while also enhancing quality of life through treatment of symptoms. The emergency physician must be aware of the ethical and medico-legal parameters that govern decision making. [http://www.emed.theclinics.com/article/S0733-8627\(14\)00065-0/abstract](http://www.emed.theclinics.com/article/S0733-8627(14)00065-0/abstract)

Noted in Media Watch, 18 August 2014, #371 (p.12):

- *PALLIATIVE MEDICINE* | Online – 12 August 2014 – '**What is the incidence of patients with palliative care needs presenting to the emergency department? A critical review.**' There is an absence of evidence regarding the incidence of patients with palliative care needs presenting to the emergency department. Further research needs to be undertaken in this area to ensure both clinicians and policymakers have sufficient information for service provision. <http://pmj.sagepub.com/content/early/2014/08/07/0269216314543318.abstract>

#### **Information preferences of the general population when faced with life-limiting illness**

*EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 22 September 2014 – Around 82% of [study] respondents wanted to be informed always about diagnosis, chances of cure and available treatments, 77% wanted to be informed on life expectancy, 72% on options regarding palliative care and 67% on possibilities of prolonging or shortening life. Around 55% wanted their relative to be informed always about diagnosis, chances of cure, life expectancy and different treatments available, whereas 50% wanted this in relation to the options regarding palliative care and 46% on the possibilities of prolonging or shortening life. Younger adults, people with more education and people with a regular GP were more likely to want to be informed always. Younger adults and women were less likely to want their relatives to be informed always. Physicians should be aware of the desired level of information and tailor information to individual patient preferences. <http://eurpub.oxfordjournals.org/content/early/2014/09/22/eurpub.cku158.abstract>

Cont.



Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 25 September 2014 – '**Managing end of life medications at home – accounts of bereaved family carers: A qualitative interview study.**' Although some support with medications is provided by GPs and nurses in the community, family carers take primary responsibility for drug administration and storage. Key barriers to managing end of life medications at home included: complex regimes; unwanted responsibility in deciding when to use "as needed" medication; disagreements with professional staff, and anxiety about medication errors, especially if perceived to have implications for survival. <http://spcare.bmj.com/content/early/2014/09/25/bmjspcare-2014-000658.short?rss=1>
- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 22 September 2014 – '**Use of quality information in decision-making about health and social care services: A systematic review.**' The analysis highlighted the use of multiple sources of information in decision-making about services and in particular the importance of informal sources and extended social networks in accessing information. There is limited awareness and use of "official" and online information sources. Service users or family carers place greater emphasis on general information and structural indicators. Clinical or quality-of-life outcomes are often difficult to interpret and apply. Trust emerged a key issue in relation to quality information. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12133/abstract>
- *PALLIATIVE MEDICINE* | Online – 23 September 2014 – '**How hospice staff members prepare family caregivers for the patient's final days of life: An exploratory study.**' There is widespread agreement that the families of hospice patients need to be prepared for the final days of life, yet current practices preparing families are not well described. The purpose of the study was to describe how hospice clinicians prepare family for the final days of life, including: 1) the content of the preparatory information; 2) strategies and timing of preparation, and whether the preparation is tailored; and, 3) who prepares families. Preparatory messages included information on signs of impending death, symptoms, implications of the symptoms, what to expect next, and instructions on what to do. Commonly used strategies included listening, engendering trust, repetition, collaboration with other disciplines, and demonstrations. <http://pmj.sagepub.com/content/early/2014/09/22/0269216314551320.abstract>

#### Elder care in Ireland

#### **A demographic time bomb**

*IRISH MEDICAL NEWS* | Online – 25 September 2014 – Several commentators have voiced concerns about the future of long-term residential care in Ireland... The Department of Health was ... never among this cacophony. But briefing notes issued to Health Minister Leo Varadkar ... state waiting times for the release of funding under the Nursing Home Support Scheme are to rise from 7-8 weeks to between 14 and 16 weeks by the end of the year. As of 19 June, 1,390 people were on the Scheme's placement list waiting on funding, with an average waiting time of 10 weeks and huge knock on-effects on delayed discharges in hospitals. The notes outline what stakeholders and reports have been saying for some time, demographics suggest an increased demand for long-term residential care in the future. Despite this growing demand, the budget for the Scheme was reduced in 2014 by €35 million to €939 million, with €23 million being transferred to community services. Government has stated its priority for 2014 is the development of an integrated care model for older people's services, with a focus on home and community care. [http://www.imn.ie/index.php?option=com\\_content&view=article&id=5725:a-demographic-time-bomb-&catid=57:clinical-news&Itemid=3](http://www.imn.ie/index.php?option=com_content&view=article&id=5725:a-demographic-time-bomb-&catid=57:clinical-news&Itemid=3)

#### [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>

## Factors influencing the provision of end-of-life care for adolescents and young adults with advanced cancer: A scoping review

*JBI DATABASE OF SYSTEMATIC REVIEWS & IMPLEMENTATION REPORTS*, 2014;12(7): 405-447. There is international recognition that cancer in young people is on the rise and that improvements in outcomes for young people lag well behind advances achieved for both children and older adults over the past 30 years. Cancer is the third leading cause of death in adolescents and young adults; however, little is known about how the end of life unfolds for those who die of the progressive disease. This is a scoping review to provide a broader picture of existing literature on this topic. Hence, assessment of methodological quality was not performed to exclude studies based on quality scores. Relatively little research was located relating to experiences and perceptions of adolescents and young adults and their carers in relation to decision making and advanced care planning. The main focus of the research was medical record review and interviews with bereaved parents. <http://joannabriggslibrary.org/index.php/jbisrir/article/view/1622>

Noted in Media Watch, 15 October 2012, #275 (p.3):

- *PEDIATRICS* | Online – 8 October 2012 – '**Allowing adolescents and young adults to plan their end-of-life care.**' Adolescents and young adults [i.e., study participants] want to be able to choose and record: 1) the kind of medical treatment they want and do not want; 2) how they would like to be cared for; 3) information for their family and friends to know; and, 4) how they would like to be remembered. The views of what should be included in an advance care planning guide were incorporated into ... 'Voicing My Choices,' that provides youth, families and providers an opportunity to reduce the silence around the dying process by allowing an opportunity to share one's voice.<sup>1</sup> The authors' provide guidance on how to incorporate this tool into care. <http://pediatrics.aappublications.org/content/early/2012/10/02/peds.2012-0663.abstract>

1. 'Voicing My Choices: A Planning Guide for Adolescents and Young Adults,' Aging with Dignity, October 2012. <http://www.agingwithdignity.org/forms/voicingmychoices.pdf>

### 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

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
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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.

## End-of-life care in England

### **Supporting family carers providing end-of-life home care: A qualitative study on the impact of a hospice at home service**

*JOURNAL OF CLINICAL NURSING* | Online – 19 September 2014 – It is suggested that the hospice at home aide service is helping patients to remain at home for the last days of their lives and is thus supporting the implementation of the End of Life Care Strategy aim to promote patient choice... Supporting family carers is clearly vital, particularly with an increasing ageing population where carers may have their own health needs. Similarly, for the "sandwich" generation of dual carers and those in employment, consideration needs to be given to what support is appropriate for their needs. An individual package of care based upon ongoing assessment of carers' needs is undoubtedly required. For end-of-life care, this re-assessment is vital, as the caring role changes over the disease trajectory. Adopting the philosophy of recognising family carers as co-workers and supporting them in this role, will help to facilitate carer empowerment and is clearly required if their needs are to be recognised and ultimately met. The policy driver to support patients to be cared for and to die at home, if they so wish, has

resulted in the reconfiguration of hospice services. The emergence of HAH teams and increased day care interventions have resulted in more options for patients and their families. However, increasing the amount of care that a family member has to provide in these circumstances needs to be adequately supported with the provision of a flexible service tailored to individual needs and delivered by appropriately trained staff. <http://onlinelibrary.wiley.com/doi/10.1111/jocn.12695/full>

#### **Extract from the *Journal of Clinical Nursing* article**

There are approximately 129 Hospice at Home (HAH) teams in England, Wales & Northern Ireland, however, no single model of a HAH service exists. Variations include out-of-hours services, rapid response teams and community teams, all comprising differing elements of care provided by medical staff and a mixture of qualified and unqualified nursing staff.

Of related interest:

- *BRITISH JOURNAL OF COMMUNITY NURSING* | Online – 3 September 2014 – '**District nurse consultations with vulnerable patients over wishes for end-of-life care.**' As part of an enhanced service under National Health Service England's Transforming Primary Care initiative, GP practices will begin to proactively case manage patients at risk of unplanned hospital admissions. At the centre of this service is a case management register and personalised care plan that indicates the patient's wishes for future care. The initiative, and particularly the asking of questions about "do not attempt resuscitation" orders and end-of-life care, has drawn the criticism of district nurses who are frequently asked to complete the personalised care plans with patients – many of whom they have not previously met. This article considers whether the template for personal care plans is reflective of the law on consent [e.g., the Mental Capacity Act 2005]. <http://www.magonlineibrary.com/doi/abs/10.12968/bjcn.2014.19.9.458>
- *PALLIATIVE MEDICINE* | Online – 23 September 2014 – '**Breaking bad news about transitions to dying: A qualitative exploration of the role of the district nurse.**' While other colleagues can avoid breaking bad news of transition to dying, district nurses have no choice if they are to provide optimal end-of-life care. While ideally placed to carry out this work, it is complex and they are unprepared for it. They urgently need carefully tailored training in this aspect of their work, to enable them to provide optimal end-of-life care. District nurses' role in breaking bad news of transition to dying was challenging, but the conversation was described as essential preparation for a good death. Four main challenges with the conversations were patients' responses to the prognosis (unawareness, denial and anger), timing the conversation, complexities of the home environment and limited preparation in this aspect of their work. <http://pmj.sagepub.com/content/early/2014/09/22/0269216314551813.abstract>

## How long is long enough, and have we done everything we should? Ethics of calling codes

*JOURNAL OF MEDICAL ETHICS* | Online – 23 September 2014 – Despite guidelines and the medical literature outlining when it is acceptable to stop resuscitation, code cessation and deciding what not to do during a code, in practice, is an art form. Familiarity with classic evidence suggesting most codes are unsuccessful may influence decisions about when to terminate resuscitative efforts, in effect enacting self-fulfilling prophecies. Code interventions and duration may be influenced by patient demographics, gender or a concern about the stewardship of scarce resources. Yet, recent evidence links longer code duration with improved outcomes, and advances in resuscitation techniques complicate attempts to standardise both resuscitation length and the application of advanced interventions. In this context of increasing clinical and moral uncertainty, discussions between patients, families and medical providers about resuscitation plans take on an increased degree of importance. For some patients, a "bespoke" resuscitation plan may be in order. <http://jme.bmj.com/content/early/2014/09/23/medethics-2013-101949.abstract>

## Music therapy and spirituality: How can I keep from singing?

*MUSIC THERAPY PERSPECTIVES* | Online – 18 September 2014 – Spirituality is a domain of health care that for some time was overlooked, with more emphasis placed on physical needs and how to treat or cure disease. Now, as the philosophy of treating the "whole person" becomes standard practice, spirituality is becoming more integrated into the approaches of healthcare providers. Specifically, for patients with a terminal diagnosis, addressing the "whole person" becomes essential in providing comprehensive care, recognizing not only the need to manage physical symptoms for comfort, but determining and treating spiritual needs with regards to impending death. Music therapy, as part of an interdisciplinary approach, can be an effective tool in meeting the needs of those who, in the face of illness and loss, are searching for meaning, hope, and acceptance. <http://mtp.oxfordjournals.org/content/early/2014/09/18/mtp.miu023.abstract>

## Researcher or nurse? Difficulties of undertaking semi-structured interviews on sensitive topics

*NURSE RESEARCHER*, 2014;22(1):27-31. When discussing care at the end of life, researchers must accept that some participants may become distressed or emotional, depending on their previous experiences. Interviews that involve sensitive topics require careful planning. The frustration and tragedy of dementia, as experienced by the family caregivers, were powerful and required the author to exert self-control to avoid being overly sympathetic and offering words of reassurance, agreement and comfort. This blurring of roles between researcher and nurse has implications for all nurse researchers who undertake qualitative interviews, particularly when an intense emotional response is likely. <http://www.ncbi.nlm.nih.gov/pubmed/25251817>

Of related interest:

- *JOURNAL OF HEALTH CARE CHAPLAINCY*, 2014;20(4):125-143. **'Competing discourses surrounding primary caregivers of hospice patients.'** Interviews revealed five major competing discourses connected physiologically to the patient's dying trajectories: 1) care versus cure; 2) prolong-life versus end-life; 3) open versus hidden; 4) theodicy; and, 5) move-on versus don't-move-on discourse. Primary caregivers negotiated these competing discourses through educating the family, by the use of black humor, spiritualizing, ignoring opposing views, and regulating conversations. Theoretical and practical implications for interventions during end-of-life communication are discussed that may help the Chaplain and families of patients negotiate issues such as signing DNRs, impromptu visits to the hospital, and... <http://www.tandfonline.com/doi/abs/10.1080/08854726.2014.913875?queryID=%24%7BresultBean.queryID%7D>

## An ethical defence of The Liverpool Care Pathway

*NURSING TIMES*, 2014;110(40):20-21. Palliative care in the U.K. has been ranked as the best in the world. However, The Liverpool Care Pathway [LCP] was criticised and phased out. This article looks at the LCP's aims, assesses the problems and how these should be tackled. Many of these problems stemmed not from the LCP itself, but its improper use. Better training on the pathway and on communication with patients and relatives could ensure it is used correctly. The Leadership Alliance for the Care of Dying People (2014) has said it is to replace the LCP with its five Priorities for Care...<sup>1,2</sup> Its main concern was that the LCP was associated with "standardised treatment and care carried out, irrespective of whether that was right for the particular person." The LACDP has not recommended a single set of support materials, preferring to allow organisations to "work it out for themselves." It therefore seems plausible that, providing they follow the Priorities for Care, using LCP guidance as intended would be largely consistent with providing high-quality end-of-life care. <http://www.nursingtimes.net/nursing-practice/specialisms/end-of-life-and-palliative-care/an-ethical-defence-of-the-liverpool-care-pathway/5075212.article?blocktitle=This-Week%27s-Practice&contentID=4386>

1. 'Independent Report: Review of Liverpool Care Pathway for dying patients [in England],' Department of Health, July 2013. [Noted in Media Watch, 22 July 2013, #315 (p.6)] <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>
2. 'One chance to get it right: Improving people's experience of care in the last few days and hours of life,' Leadership Alliance for the Care of Dying People, June 2014. [Noted in Media Watch, 30 June 2014, #364 (p.7)] <https://www.gov.uk/government/publications/liverpool-care-pathway-review-response-to-recommendations>

## Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study

*PALLIATIVE MEDICINE* | Online – 19 September 2014 – In Phase 1, examples of good practice were apparent. However, partnership practice was infrequent and unmet educational needs were identified. Four themes emerged from the interviews in Phase 2: 1) challenges and issues in end-of-life care; 2) sharing and learning; 3) supporting and empowering; and, 4) partnership in practice. Joint working and learning between intellectual disability and specialist palliative care were seen as key and fundamental. A framework for partnership practice between both has been developed which could have international applicability and should be explored with other services in end-of-life-care. <http://pmj.sagepub.com/content/early/2014/09/17/0269216314550373.abstract>

Of related interest:

- *BRITISH JOURNAL OF LEARNING DISABILITIES* | Online – 22 September 2014 – '**Surveying community nursing support for persons with an intellectual disability and palliative care needs.**' Those delivering care expressed challenges including, understanding communication styles, late referrals, lack of time, knowledge and skills. Highlighted within the study were the benefits of liaison between family and professional and nonprofessional carers. <http://onlinelibrary.wiley.com/doi/10.1111/bld.12105/abstract;jsessionid=38C0E8C7CDF052F468F9BF41A4D88180.f03t02?deniedAccessCustomisedMessage=&userIsAuthenticated=false>

Noted in Media Watch, 4 August 2014, #369 (p.8):

- *BMJ SUPPORTIVE PALLIATIVE CARE* | Online – 29 July 2014 – '**The nature and importance of quality of therapeutic relationships in the delivery of palliative care to people with intellectual disabilities.**' Palliative care and intellectual disability staff [i.e., study participants] commented on the importance of trust, of continuity of relationship, and of knowing the individual. However, palliative care staff admitted to difficulties in these areas... <http://spcare.bmj.com/content/early/2014/07/29/bmjspcare-2013-000619.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)

**N.B.** Additional articles on end-of-life care for people living with intellectual disabilities noted in past issues of Media Watch are noted in this issue of the weekly report.

### **Infants' best interests in end-of-life care for newborns**

*PEDIATRICS* | Online – 22 September 2014 – Pediatric bioethics presumes that decisions should be taken in the child's best interest. If it's ambiguous whether a decision is in the child's interest, we defer to parents. Should parents be permitted to consider their own interests in making decisions for their child? In The Netherlands, where neonatal euthanasia is legal, such questions sometimes arise in deciding whether to hasten the death of a critically ill, suffering child. The authors describe the recommendations of a national Dutch committee. New national recommendations ... for end-of-life decisions in newborns suggest treatment should generally be seen as conditional. If treatment fails, it should be abandoned. In those cases, palliative care should be directed at both infant and parental suffering. Sometimes, this may permit interventions that hasten death. <http://pediatrics.aappublications.org/content/early/2014/09/17/peds.2014-0780.abstract>

Noted in Media Watch, 20 February 2012, #241 (p.8):

- *EARLY HUMAN DEVELOPMENT*, 2012;88(2):73-77. '**Palliative care for the newborn in the U.K.**' Palliative care for the newborn is a developing area. There are more than 2,000 estimated neonatal deaths each year in the U.K. from causes likely to benefit from palliative care. <http://www.sciencedirect.com/science/article/pii/S0378378211003793>

### **Negotiating futility, managing emotions: Nursing the transition to palliative care**

*QUALITY HEALTH RESEARCH* | Online – 22 September 2014 – Nurses play a pivotal role in caring for patients during the transition from life-prolonging care to palliative care. This is an area of nursing prone to emotional difficulty, interpersonal complexity, and interprofessional conflict. It is situated within complex social dynamics, including those related to establishing and accepting futility and reconciling the desire to maintain hope. Drawing on interviews with 20 Australian nurses, the authors unpack their accounts of nursing the transition to palliative care, focusing on the purpose of nursing at the point of transition; accounts of communication and strategies for representing palliative care; emotional engagement and burden; and, key interprofessional challenges. In caring for patients approaching the end of life, nurses occupy precarious interpersonal and interprofessional spaces that involve a negotiated order around sentimental work, providing them with both capital (privileged access) and burden (emotional suffering) within their day-to-day work. <http://qhr.sagepub.com/content/early/2014/09/22/1049732314553123.abstract>

Of related interest:

- *PALLIATIVE MEDICINE* | Online – 23 September 2014 – '**Palliative Care Phase: Inter-rater reliability and acceptability in a national study.**' The concept of palliative care consisting of five distinct, clinically meaningful, phases (stable, unstable, deteriorating, terminal and bereavement) was developed in Australia about 20 years ago and is used routinely for communicating clinical status, care planning, quality improvement and funding. [The aim of this study was to] ... test the reliability and acceptability of revised definitions of Palliative Care Phase. <http://pmj.sagepub.com/content/early/2014/09/22/0269216314551814.abstract>



## Media Watch Online

### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/9/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](http://www.ipcrc.net/archive-global-palliative-care-news.php) to access the weekly report]

### **Canada**

ALBERTA HOSPICE PALLIATIVE CARE ASSOCIATION: <http://ahpca.ca/> (Scroll down to 'Media Watch')

ONTARIO | Central Regional Hospice Palliative Care Program: <http://www.centralrhpcp.ca/Physicians/resources.htm?mediawatch=1>

ONTARIO | Central West Palliative Care Network: [http://cwpcn.ca/Health\\_Practitioners/resources.htm?mediawatch=1](http://cwpcn.ca/Health_Practitioners/resources.htm?mediawatch=1)

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

ONTARIO | Mississauga Halton Palliative Care Network: <http://www.mhpcn.ca/Physicians/resources.htm?mediawatch=1>

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

### **Europe**

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

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

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

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