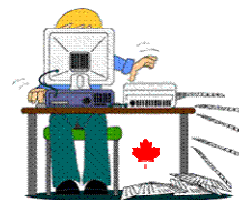


## Media Watch...

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

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Compiled & Annotated by Barry R. Ashpole

The illness experience: Scroll down to [Specialist Publications](#) and 'Benefits of health and social care integration' (p.8), in *BMJ Supportive & Palliative Care*.

## Canada

### New Democratic Party MP wants to close cracks in palliative care

ONTARIO | *The Regina Leader-Post* (Saskatchewan) – 22 March 2014 – Charlie Angus ... wants palliative care to be an issue that crosses political party lines. Angus has proposed motion M-456 calling on the federal government to establish a Pan-Canadian palliative and end-of-life care strategy with the provinces and territories. The bill will be debated in the House of Commons on 1 April. "We're taking the language right out of an all-party parliamentary committee that said there needs to be a national co-ordinating plan. I'm hoping the other parties will support it," said Angus.<sup>1</sup> <http://www.leaderpost.com/health/wants+close+cracks+palliative+care/9648897/story.html>

1. 'Not to be Forgotten: Care of Vulnerable Canadians,' Ad Hoc (All Party) Parliamentary Committee on Palliative & Compassionate Care. [Noted in Media Watch, 21 November 2011, #228 (p.1)] <http://pcpcc-cpspsc.com/wp-content/uploads/2011/11/ReportEN.pdf>

### Medical debate over defining death has implications for organ donors

BBC NEWS (U.K.) | Online – 21 March 2014 – The standards for defining death in Canada vary so much that the hospital where a dying person ends up may affect when they are declared dead – and that has some Canadian doctors concerned about the implications for organ donation, CBC's *the fifth estate* has learned.<sup>1</sup> There are about 2,000 organs transplanted in Canada every year, but hundreds of people die while on a waiting list because of a critical shortage of life-saving organs. Across the country, physicians involved in organ donation must adhere to what's known as the "dead donor rule." It seems simple – organs cannot be procured until after the donor has died. The problem is how to pinpoint the exact time of death, says the University of Alberta's director of critical care, Dr. David Zygun. "The challenge is that death is a process, and when it's a process, taking it to one specific time is very difficult," he told *the fifth estate*'s Bob McKeown. The result is that the length of time before a person can be officially declared dead in Canada and around the world may depend less on medical science than where the hospital is located. <http://www.cbc.ca/news/health/medical-debate-over-defining-death-has-implications-for-organ-donors-1.2579992>

1. 'Dead Enough, CBC *the fifth estate*: <http://www.cbc.ca/fifth/>

Cont.

Noted in Media Watch, 3 September 2012, #269 (p.1):

- **THE NATIONAL POST** | Online – 28 August 2012 – '**Legally dead' may still be alive: Warning over new organ-donor guidelines.**' Months into the latest national campaign to recruit ... organ donors, a legal scholar is arguing that new guidelines for declaring people brain dead and eligible for organ harvesting likely violate the Charter of Rights & Freedoms.<sup>1</sup>  
<http://news.nationalpost.com/2012/08/28/canadas-new-organ-donor-rules-likely-violate-the-charter-legal-expert/>
- 1. 'Section 7 Charter implications of the Canadian Council for Donation & Transplantation's guidelines for the neurological determination of death,' *McGill Journal of Law & Health*, 2012;6(1):41-136. <http://mjlh.mcgill.ca/pdfs/vol6-1/MJLH%20Vol.%206.%20No.%201%20-%20Shaw.pdf>

## U.S.A.

### **Medicare to test new approach to hospice care**

**KAISER HEALTH NEWS** | Online – 18 March 2014 – Medicare will test a program to allow terminally ill people to get hospice and more aggressive care at the same time, a model long championed by advocates for better end-of-life care. People on Medicare can get hospice care if they have a life expectancy of six months or less, but many end up in hospice for only a few days, if that. The "either/or" approach – hospice or aggressive care – is widely seen as a barrier to hospice use. The new program will test the idea that "concurrent care" can expand patients' choices, giving them the option of both palliative care and intense treatment without costing more.  
<http://www.kaiserhealthnews.org/Daily-Reports/2014/March/19/medicare-cost-and-quality-issues.aspx>

#### Specialist Publications

**'The growth of palliative care in the U.S.'** (p.7), in *Annual Review of Public Health*.

### **Late-in-life care: Fragmentation and complexity for the chronically ill**

**THE MINNESOTA POST** (Minneapolis) | Online – 18 March 2014 – Fragile individuals who have months or years to live find themselves in a profoundly fragmented and confusing health-care system where they too often are treated as disease cases rather than individuals with personal wishes and practical needs. "We have a health-care system that is great if you have a sudden heart attack or you come down with pneumonia," said Dr. Diane Meier, of the Center to Advance Palliative Care at the Icahn School of Medicine at Mount Sinai in New York. "But it's completely useless during the 10 years that you are living with progressive chronic disease and you need help at home," said Meier, who is also a national adviser to Alina Health's Robina LifeCourse Project, one of several efforts under way nationwide to

test models for delivering more supportive, whole-person care to seriously ill patients...  
<http://www.minnpost.com/health/2014/03/late-life-care-fragmentation-and-complexity-chronically-ill>

#### **Extract from *The Minnesota Post* article**

While the U.S. spends more on health care than other developed countries, it spends far less on related social services. Other countries in the Organisation for Economic Co-operation & Development provide an average of \$2 worth of supportive services for every dollar spent on health care. That is twice the amount the U.S. spends per health-care dollar...

Cont.

Representative sample of articles on integration of health and social services in the U.K. noted in past issues of Media Watch:

- *BRITISH MEDICAL JOURNAL* | Online – 19 June 2013 – **'Independent commission will look at split between health and social care in England.'** An independent commission to consider the future of health and social care in England has been set up by the health think tank the King's Fund, which aims to publish the findings in time for the 2015 general election. [Noted in Media Watch, 24 June 2013, #311 (p.8)] <http://www.bmj.com/content/346/bmj.f3973>
- *HEALTH & SOCIAL CARE IN THE COMMUNITY* | Online – 11 June 2013 – **'Factors that promote and hinder joint and integrated working between health and social care services: A review of research literature.'** Findings suggest there is some indication recent developments, in particular the drive to greater integration of services, may have positive benefits for organisations as well as for users and carers of services. [Noted in Media Watch, 17 June 2013, #310 (p.13)] <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12057/abstract>

**Specialist Publications**

**'Benefits of health and social care integration'** (p.8), in *BMJ Supportive & Palliative Care*.

**Policy disclosure: End-of-life care**

**Washington's rule on "transparent" hospital policies gets enmeshed in controversy**

STATE OF WASHINGTON | *Puget Sound Business Journal* – 18 March 2014 – New state regulations require hospitals to disclose their policies on a number of issues to the Department of Health... The department has already begun to post on its website hospital policies on admissions, non-discrimination, end-of-life care and reproductive health care. The new rules are intended to provide transparency for patients in cases of hospital mergers and affiliations, particularly those involving Catholic hospitals. Governor Jay Inslee called for a change in the review process ... because of public concern that Catholic health systems that merge with secular hospitals could limit access to services such as reproductive and end-of-life care. Although a handful of the nearly 100 hospitals on the Health Department's list have already submitted their policies, the new rules are enmeshed in controversy. Many groups object to the rules, saying that this process doesn't provide patients with the right information. <http://www.bizjournals.com/seattle/blog/health-care-inc/2014/03/washingtons-rule-on-transparent-hospital-policies.html>

Noted in Media Watch, 16 December 2013, #336 (p.3):

- ABC NEWS | Online – 9 September 2013 – **'Debate over Catholic directives that affect 13% of U.S. hospitals.'** Every Catholic hospital and Catholic healthcare institution must adhere to *Ethical & Religious Directives for Catholic Health Care Services* or risk losing their classification as a Catholic institution.<sup>1</sup> The guidelines cover such issues as end-of-life care... <http://abcnews.go.com/Health/catholic-bishops-influence-healthcare-catholic-hospitals/story?id=21123027>
  1. *Ethical & Religious Directives for Catholic Health Care Services*, 5<sup>th</sup> Edition, United States Conference of Catholic Bishops, 17 November 2009. [Noted in Media Watch, 6 January 2014, #339 (p.8)] <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>

**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.11.

## Myths about palliative care persist among Indian American immigrants

CALIFORNIA | *New America Media* (San Francisco) – 17 March 2014 – Major misperceptions about palliative and hospice care persist in immigrant communities, including the Indian American community, according to palliative care health professionals. "It is a major concern that those in immigrant communities equate palliative care services with near death and end-of-life treatments," said Suresh Reddy, section chief and director of education of the Department of Symptom Control & Palliative Care at the M.D. Anderson Cancer Center in Houston, Texas. "And a lot of [Asian immigrants] don't even want to hear the term hospice. They definitely view that as a death place," he said. <http://newamericamedia.org/2014/03/myths-about-palliative-care-persist-among-indian-american-immigrants.php>

Noted in Media Watch, 3 October 2011, #221 (p.10):

- *JOURNAL OF GENERAL INTERNAL MEDICINE* | Online – 24 September 2011 – '**Traditional expectations versus U.S. realities: First- and second-generation Asian Indian perspectives on end-of-life care.**' Traditional cultural values, such as duty to family, greatly influenced end-of-life care preferences and retained importance across generations. Clinicians caring for Asian Indian patients may be better able to assess care preferences after exploring the complex interplay between traditional expectations and specific social realities for each patient. <http://www.springerlink.com/content/c31g0504304367tu/>

## An army of caregivers with no basic training

OKLAHOMA | *Tulsa World* – 16 March 2014 – At 600,000 strong, family caregivers in Oklahoma outnumber the entire active-duty U.S. Army. They've answered the call of duty and tasked themselves with helping friends or relatives stay in the place they most want to be — home. Yet many of these unsung heroes ... feel overwhelmed and ill-equipped to deal with the needs of those they help — especially after hospital stays. This challenge is not lost on Senator Brian Crain ... who is pushing Senate Bill 1536, which would make sure that family caregivers receive the training they need to care properly for their loved ones after they leave a hospital. The bill also would allow patients to designate a caregiver at the time of hospital admission. The Senate has approved the bill and it moves on to the House, where lawmakers should give it the same careful consideration. The well-being of thousands of vulnerable Oklahomans is on the line. The measure also could give caregivers peace of mind. Training at a hospital would not turn any of them into nurses or physicians. It might, however, give them some tools and skills to better handle situations they face at home. [http://www.tulsaworld.com/opinion/juliedelcour/julie-delcour-an-army-of-caregivers-with-no-basic-training/article\\_56ab7207-d8c0-5c83-a89c-7f76136c2818.html](http://www.tulsaworld.com/opinion/juliedelcour/julie-delcour-an-army-of-caregivers-with-no-basic-training/article_56ab7207-d8c0-5c83-a89c-7f76136c2818.html)

Noted in Media Watch, 1 August 2011, #212 (p.4):

- *FORBES* | Online – 26 July 2011 – '**New stipend program for caregivers of veterans disperses first payments.**' Family members caring for veterans received their first payments from the U.S. Department of Veterans Affairs' Family Caregiver Program. Nearly 200 family caregivers completed the required training program in time to receive a stipend in July. <http://blogs.forbes.com/bernardkrooks/2011/07/25/new-stipend-program-for-caregivers-of-veterans-disperses-first-payments/>

## West Virginia online registry allows users to file end-of-life wishes

WEST VIRGINIA | *The Charleston Gazette* – 15 March 2014 – The West Virginia Center for End-of-Life Care, an agency funded through the state Department of Health & Human Resources' Bureau for Public Health, experienced a record-setting year in 2013. The agency's e-Directive Registry, which allows users to file online for advance directives related to end-of-life care, has seen a spike in filings since its launch in 2012. The directory received 10,836 forms in 2013, a 35% increase from its 2012 submissions. <http://www.wvgazette.com/News/201403150088>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

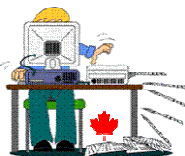
- CONNECTICUT | *My Record-Journal* (Meriden) – 18 March 2014 – **'Legislators: Vote unlikely this year on assisted suicide bill.'** Area state legislators on both sides of the assisted suicide debate say there's little support for an "aid in dying" bill<sup>1</sup> currently being discussed in the General Assembly's Public Health Committee. A similar bill last year but didn't come up for a vote. <http://www.myrecordjournal.com/southington/southingtonnews/3970397-129/legislators-vote-unlikely-this-year-on-assisted-suicide-bill.html>
  1. Connecticut Bill 5326, 'An Act concerning compassionate aid in dying for terminally ill patients.' <http://www.cga.ct.gov/2014/TOB/H/2014HB-05326-R00-HB.htm>
- MASSACHUSETTS | Associated Press (Boston) – 18 March 2014 – **'Assisted suicide bill appears stalled...'** The Public Health Committee [has] recommended the [proposed] bill be sent to a study committee,<sup>1</sup> a common way of essentially ensuring no action will be taken before the end of the formal session. In 2012, a ballot question that would also have allowed patients to self-administer life-ending drugs prescribed by physicians was narrowly defeated. <http://www.wqgb.com/2014/03/18/assisted-suicide-bill-appears-stalled-on-beacon-hill/>
  1. Massachusetts Bill H.1998, 'An Act affirming a terminally ill patient's right to compassionate aid in dying.' <https://malegislature.gov/Bills/188/House/H1998>

## International

### One-third of hospital patients "die within 12 months"

U.K. (Scotland) | *The Herald* (Edinburgh) – 19 September 2014 – Almost one in three people receiving hospital treatment are likely to die within 12 months, a study of nearly 11,000 patients has found.<sup>1</sup> Researchers from the University of Glasgow who followed the progress of patients at 25 hospitals across Scotland found 28.8% died within a year. The study, carried out with a view to informing end-of-life care strategies in hospital, examined the age, health and treatment of patients on one day. Of the patients involved, 2.9% died within a week, 16% within three months and 25.5% within nine months. The study found men were more likely to die than women, as were patients over 85 compared to those under 60. Professor David Clark, head of the school of interdisciplinary studies at the university, said that the research showed there was a need for hospitals to adopt a more vigorous approach to identifying patients who are entering the last year of their lives. <http://www.heraldscotland.com/news/home-news/one-third-of-hospital-patients-die-within-12-months.23732974>

1. 'Imminence of death among hospital inpatients...'*Palliative Medicine*, 17 March 2014. There is a dearth of evidence on the proportion of the hospital population at any one time, that is in the last year of life, and therefore on how hospital policies and services can be oriented to their needs. <http://pmj.sagepub.com/content/early/2014/03/17/0269216314526443.abstract>



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### **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>

Noted in Media Watch, 19 September 2011, #219 (p.9):

- *JOURNAL OF CLINICAL ONCOLOGY* | Online – 12 September 2011 – '**Information of imminent death or not: Does it make a difference?**' Providing information of imminent death to a patient with cancer at the end of life does not seem to increase pain or anxiety, but it does seem to be associated with improved care and increase the likelihood of fulfilling the principles of a good death. <http://jco.ascopubs.org/content/early/2011/09/11/JCO.2011.34.6247.abstract>

#### Advance care planning in Australia

#### **Lawyer questions Northern Territory's new "living wills"**

AUSTRALIA (Northern Territory) | ABC News (Darwin) – 18 March 2014 – Professor Loane Skene, from the University of Melbourne, an expert in medical law, says that while she generally supports the concept of living wills, she had reservations about making the documents legally binding. "I think it is less problematic if they are not legally binding," Professor Skene told ABC News. She said that some of the language in the documents such as "it is reasonably certain that I will not recover" and "medically appropriate" could be open to interpretation and cause legal problems for doctors. Professor Skene also said doctors could be left between a rock and a hard place if patients put contradictory information in the documents,

such as requesting no life support systems be used, but also saying they wanted CPR, which could be seen as a type of life support. As people aged they may also be more willing to put up with different treatments to prolong their life, so problems may arise if people have changed their minds since they filled in the papers, Skene said. <http://www.abc.net.au/local/stories/2014/03/18/3966441.htm?site=darwin>

#### Specialist Publications

'Patient advance directives in practice' (p.10), in *Deutsches Ärzteblatt International*.

Of related interest:

- AUSTRALIA (Victoria) | *The Age* (Melbourne) – 16 March 2014 – '**Death with dignity reform.**' Victorians will be able to instruct their doctors to not give them life-prolonging treatment for possible future illnesses, under a state government push to allow people to die with dignity. As a condition of hospital funding, patients will now be encouraged to create "advance care plans..." <http://www.theage.com.au/victoria/death-with-dignity-reform-20140315-34udp.html>

#### Elder care in Australia

#### **Informal care "a ticking time bomb"**

AUSTRALIAN AGEING AGENDA | Online – 18 March 2014 – Australia's health and aged care systems must acknowledge the country's 2.6 million unpaid carers and work with them as "partners in care," a group of healthcare organisations argue in a new paper. They called for increased collaboration and coordination in the delivery of care, and improved education for carers providing home healthcare. The *Defusing a Ticking Time Bomb* white paper calls on government to deliver a wide range of responses to better support carers, who collectively provide \$40 billion worth of unpaid care at home to frail aged, chronically ill and those with a disability. It said the current system of volun-

tary home care, which it described as "anti-quoted" and at a "tipping point," was unable to cope with the projected 250% increase in demand over the next forty years. <http://www.australianageingagenda.com.au/2014/03/18/informal-care-ticking-time-bomb/>

#### Specialist Publications

'Burden on family carers and care-related financial strain at the end of life: A cross-national population-based study,' (p.12), in *European Journal of Public Health*.



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

### **The growth of palliative care in the U.S.**

*ANNUAL REVIEW OF PUBLIC HEALTH*, 2014;35:459-475. The benefits of palliative care have now been shown in multiple clinical trials, with increased patient and provider satisfaction, equal or better symptom control, more discernment of and honoring choices about place of death, fewer and less intensive hospital admissions in the last month of life, less anxiety and depression, less caregiver distress, and cost savings. The cost savings come from cost avoidance, or movement of a patient from a high cost setting to a lower cost setting. Barriers to expanded use include physician resistance, unrealistic expectations of patients and families, and lack of workforce. The future of palliative care includes more penetration into other fields such as nephrology, neurology, and surgery; further discernment of the most effective and cost-effective models; and establishment of more outpatient services. <http://www.annualreviews.org/doi/abs/10.1146/annurev-publhealth-032013-182406>

### Pediatric palliative care in the U.S.

#### **St. Jude Children's Research Hospital committee identifies eight palliative care priorities in pediatric oncology**

*ASCO POST* (American Society of Clinical Oncology), 2014;5(5). About 2½ years ago, St. Jude Children's Research Hospital in Memphis conducted a series of focus groups to better understand the palliative care priorities of bereaved parents. Their findings were never intended to be generalized, but rather to be used to formulate a strategic plan for an institutional palliative care initiative. Because pediatric oncology issues are best addressed in a family-centered care manner, the authors strongly recommend the formation of institutional task forces formed by pediatric oncology leaders, health-care providers, and family members to promptly identify strategies to evaluate and improve these aspects of care. <http://www.ascopost.com/issues/march-15,-2014/st-jude-children%E2%80%99s-research-hospital-committee-identifies-eight-palliative-care-priorities-in-pediatric-oncology.aspx>

#### **Artificial nutrition at the end of life: Ethical issues**

*BEST PRACTICE & RESEARCH CLINICAL GASTROENTEROLOGY* | Online – 12 March 2014 – Artificial nutrition is a medical treatment that first of all needs a sound scientific base before prescribing it. This base is absent for dying patients and patients in the end stage of dementia. Because feeding is a very emotional and symbolical issue, patient and family may request this treatment despite the lack of evidence. These issues should be addressed in good communication with patient and relatives. For comatose patients and patients in a persistent vegetative state artificial nutrition is a necessary support to bridge the time until either recovery is imminent or improbable. At that moment artificial nutrition no longer contributes to the life of the patient and should be ceased. Artificial nutrition has no place in patients that voluntarily decide to stop eating and drinking in order to die. <http://www.sciencedirect.com/science/article/pii/S1521691814000213>

Of related interest:

- *BMJ SUPPORTIVE & PALLIATIVE CARE* | Online – 17 March 2014 – **'What influences attitudes towards clinically assisted hydration in the care of dying patients? A review of the literature.'** Developing international evidence suggests that cultural norms and ethical principles of a family, population or healthcare environment influence attitudes towards CAH [clinically assisted hydration], particularly where CAH has symbolic meaning; representing care, hope and trust. There is surprisingly little robust evidence regarding dying patients, or the wider general public's views, on the perceived value of CAH in the last days and hours of life. <http://spcare.bmj.com/content/early/2014/03/17/bmjspcare-2013-000562.abstract>

Cont.

Noted in Media Watch, 3 February 2014, #343 (p.6):

- *JOURNAL OF MEDICAL ETHICS* | Online – 14 January 2014 – **'Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: Family perspectives.'** Most medical ethicists have treated the issue as one of life versus death; by contrast, families [i.e., study participants] – including those who believed that their relative would not have wanted to be kept alive – focused on the manner of the proposed death and were often horrified at the idea of causing death by "starvation and dehydration." <http://jme.bmj.com/content/early/2014/01/03/medethics-2013-101799.abstract?sid=e163ee08-9328-48f7-ae13-eca744f64b71>

### **Benefits of health and social care integration**

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(18). Scotland's health boards and local authorities are moving towards integrated funding and service provision. Effective integration will depend on health, social care and third/independent sector partners pooling resources and planning care together, led by clinicians and other professionals. Over seventy-seven patients [i.e., study participants] would have required hospital admission without the integrated service [i.e., Integrated Health & Personal Care Community Support]. Eight-three percent of respondents thought the service had enabled more input into decision making about their care; and, 66% were able to spend more time with their loved ones and have reported an improved quality of life. The voluntary sector is a key partner in supporting the integration agenda with specific expert knowledge. <http://spcare.bmj.com/content/4/1/118.1.short>

Noted in Media Watch, 13 May 2013, #305 (p.13):

- *HEALTH SERVICE JOURNAL* | Online – 8 May 2013 – **'Redesigning end of life care in the community.'** The challenges for the health and social care system in our rapidly ageing society and the pressure associated with ongoing public spending constraints are clear for all to see. Faced with these twin challenges, we can either stand by and oversee a gradual decline in the quality of care provided or we can seize the opportunity to fundamentally change the way we do things. <http://www.hsj.co.uk/home/innovation-and-efficiency/redesigning-end-of-life-care-in-the-community/5057553.article?blocktitle=Resource-Centre&contentID=8630>

### **How well do the general public understand palliative care? A mixed methods study**

*BMJ SUPPORTIVE & PALLIATIVE CARE*, 2014;4(Suppl). International research suggests the general public appear to be confused about what palliative care is and who provides it. An understanding of public views is needed in order to target education and policy campaigns and to manage future needs, expectations and resourcing of care. Responses indicated limited knowledge about palliative care. Respondents who worked in healthcare themselves or who had a close relative or friend who had used a palliative care service were more aware of palliative care and the availability of different palliative care services. The main barriers to raising awareness were fear, lack of interaction with health services and perception of lack of resources. [http://spcare.bmj.com/content/4/Suppl\\_1/A2.1.abstract](http://spcare.bmj.com/content/4/Suppl_1/A2.1.abstract)

### **Place of death in the Czech Republic and Slovakia: A population based comparative study using death certificates data**

*BMC PALLIATIVE CARE* | Online – 20 March 2014 – The majority of population in both countries died in hospitals (58.4% the Czech Republic, 54.8% Slovakia), less than one-third died at home. In case of chronic conditions, death at home was significantly associated with underlying cause of death (cancer and heart failure), being male, age (older than 85, Slovakia only) and higher education (the Czech Republic only). Cancer and heart failure patients had higher chances to die at home than other chronic conditions. <http://www.biomedcentral.com/content/pdf/1472-684X-13-13.pdf>

Cont.



Noted in Media Watch, 25 February 2013, #294 (p.7):

- *CLINICAL SOCIAL WORK*, 2012;4(3):5-8. '**Current palliative and hospice care in Slovakia.**' Palliative and hospice care is generally not affordable and ill people cannot afford the place where they would like to end their lives. We still do not get necessary and true information about the diagnosis and the prognosis, palliative home care is not supported, and professional support for those who would like to assist a dying person at home is missing. [http://www.clinicalsocialwork.eu/userfiles/CSW\\_4\\_2012\\_v5\\_3.pdf#page=7](http://www.clinicalsocialwork.eu/userfiles/CSW_4_2012_v5_3.pdf#page=7)

Noted in Media Watch, 10 October 2011, #222 (p.5):

- CZECH REPUBLIC | *Prague Daily Monitor* – 5 October 2011 – '**Poll: Most Czechs wish to die at home, few do so.**' Seventy-eight percent of Czechs would like to die at home, but very few do so, according the institute STEM/MARK. <http://praguemonitor.com/2011/10/05/poll-most-czechs-wish-die-home-few-do-so>

### **Ethical challenges of deactivation of cardiac devices in advanced heart failure**

*CURRENT HEART FAILURE REPORTS* | Online – Accessed 18 March 2014 – Patients who have an ICD [implantable cardioverter defibrillator] may be denied the chance of a sudden cardiac death, and instead are committed to a slower terminal decline, with frequent DC shocks that can be painful and decrease the quality of life, greatly contributing to their distress and that of their families during this period. While patients with ICDs are routinely counseled with regard to the benefits of ICDs, they have a poor understanding of the options for device deactivation and related ethical and legal implications. Deactivating an ICD or not performing a generator change is both legal and ethical, and is supported by guidelines from both sides of the Atlantic. <http://link.springer.com/article/10.1007/s11897-014-0194-8>

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#### [Media Watch: Editorial Practice](#)

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

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#### [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.

Noted in Media Watch, 3 February 2014, #343 (p.2):

- *JAMA INTERNAL MEDICINE*, 2014;174(1):80-85. **'Features and outcomes of patients who underwent cardiac device deactivation.'** [In this retrospective review of medical records] advance directives executed by patients with these devices rarely addressed device management. <https://archinte.jamanetwork.com/article.aspx?articleid=1783304>

Noted in Media Watch, 27 February 2012, #242 (p.13):

- *THEORETICAL MEDICINE & BIOETHICS*, 2012;33(6):421-433. **'Pacemaker deactivation: Withdrawal of support or active ending of life?'** The authors argue that clinicians uncomfortable with pacemaker deactivation are nevertheless correct to see it as incompatible with the traditional medical ethics of withdrawal of support. Traditional medical ethics is presently taken by many to sanction pacemaker deactivation when such deactivation honors the patient's right to refuse treatment. <http://link.springer.com/article/10.1007/s11017-012-9213-5>

**N.B.** Footnoted in this issue of Media Watch is additional articles on ethical issues on defibrillator deactivation in end-of-life care noted in past issues of the weekly report.

### End-of-life care in Germany

#### **Patient advance directives in practice**

*DEUTSCHES ÄRZTEBLATT INTERNATIONAL*, 2014;111(4):48-49. It should be emphasized that this is the first study anywhere in the world to report the efficacy of the implementation of a regional ACP [advance care planning] program.<sup>1</sup> The intervention focused not on the institution, but on the region. One central finding is that many more advance directives were written than before, and the directives were characterized by much greater clarity and validity. This encourages introduction of the intervention to other regions – despite the time and effort required. The authors' conclusion, namely that implementation of the ACP program in nursing homes led to more operationally effective advance directives being written than in the control region, underlines the desirability of expanding ACP to other regions where it can again be tested in practice. Expanded implementation of ACP and evaluation of its effects can indeed help to ascertain the consequences for day-to-day care of the elderly in practice. The results published here justify such expansion. In the medium term, they will help to resolve the question of what resources an ACP program demands and what savings it enables. <https://www.aerzteblatt.de/pdf/DI/111/4/m48.pdf>

1. 'Implementing an advance care planning program in German nursing homes...', *Deutsches Ärzteblatt International*, 2014;111(4):50-57. [Noted in Media Watch, 17 February 2014, #345 (p.9)] <http://www.aerzteblatt.de/pdf.asp?id=152957>

Of related interest:

- *THE HASTINGS REPORT*, 2014;44(2):3. **'Why we need to acknowledge the multiple aims of advance care planning.'** People do not exercise their autonomy in a vacuum, and the desire to reduce health care costs cannot be represented as a side issue in the debate about advance care planning. Improving end-of-life care and promoting patient autonomy may together be the most palatable reason to pursue advance care planning, but they are unlikely to be the only reason for implementing policy changes that foster advance care planning initiatives or for funding advance care planning programs. Ignoring the ethical problems raised by the desire to reduce health care costs will ultimately undermine advance care planning initiatives and policies. <http://onlinelibrary.wiley.com/doi/10.1002/hast.272/full>

**N.B.** This article is a commentary on 'What's not being shared in shared decision-making?' *The Hastings Report*, 2013;43(4):13-16. [Noted in Media Watch, 15 July 2014, #314 (p.7)] <http://onlinelibrary.wiley.com/doi/10.1002/hast.188/abstract>

Cont.

- *JOURNAL OF GERONTOLOGICAL NURSING* | Online – 18 March 2014 – '**Prevalence, views, and impact of advance directives among older adults.**' Despite increasing advance directive completion as patients move from community to nursing homes to hospice, advance directives are often insufficiently detailed and current for health care professionals to be confident they are acting in accordance with what patients would choose for themselves. <http://www.healio.com/nursing/journals/jgn/%7Bf0e9c2ea-a830-4cef-b018-e59ea958db0b%7D/prevalence-views-and-impact-of-advance-directives-among-older-adults>
- *NURSING RESEARCH & PRACTICE* | Online – Accessed 20 March 2014 – '**A review of advance care planning programs in long-term care homes: Are they dementia friendly?**' Six advance care planning programs were included in this review, five of which could be considered more "dementia friendly." <file:///C:/Users/Barry/Downloads/875897.pdf>

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### Media Watch Online

#### **International**

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE: <http://hospicecare.com/about-iahpc/newsletter/2014/3/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**

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://www.hpcconnection.ca/newsletter/inthenews.html>

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://www.hospicehaz.hu/en/training/> [Scroll down to 'Media Watch']

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>

- *PALLIATIVE MEDICINE* | Online – 20 March 2014 – **'The effects of advance care planning on end-of-life care: A systematic review.'** Complex advance care planning interventions may be more effective in meeting patients' preferences than written documents alone. More studies are needed with an experimental design, in different settings, including the community. <http://pmj.sagepub.com/content/early/2014/03/20/0269216314526272.abstract>

**Burden on family carers and care-related financial strain at the end of life: A cross-national population-based study**

*EUROPEAN JOURNAL OF PUBLIC HEALTH* | Online – 17 March 2014 – The authors studied 4,466 deaths. GPs judged family carers of 28% (Belgium), 30% (The Netherlands), 35% (Spain) and 71% (Italy) of patients as physically/emotionally overburdened. For 8% (Spain), 14% (Belgium), 36% (The Netherlands) and 43% (Italy) patients, GPs reported difficulties in covering care-related costs. Patients <85 years of age (Belgium, Italy) had higher odds of having physically/emotionally overburdened family carers and financial burden. Death from non-malignant illness (vs. cancer) (Belgium and Italy) and dying at home compared with other locations (The Netherlands and Italy) were associated with higher odds of difficulties in covering care-related costs. In all countries studied, and particularly in Italy, GPs observed a considerable extent of physical/emotional overburden as well as difficulties in covering care-related costs among family carers of people at the end of life. Implications for health- and social care policies are discussed. <http://eurpub.oxfordjournals.org/content/early/2014/03/17/eurpub.cku026.abstract>

**Bad words: Clinical case study about the desires of a patient to prolong her life and the doctors to communicate with her only using "positive" language**

*THE HASTINGS REPORT*, 2014;44(2):13-14. The clinical ethicist met with Ms. H to clarify what information she wants and does not want to know. She wants to receive any treatment that could prolong her life, regardless of how the treatment affects her ability to engage in activities of daily living. She wants to be included in the decision-making process as much as possible, as long as clinicians use only "positive" language. Ms. H. considers the words "dying," "chemotherapy," "radiation" and "cancer" to be "bad words." For conversations in which these words cannot be avoided, she wants her clinicians to talk to her son. Her desired engagement includes hearing about risks, benefits, and alternatives to treatments if clinicians use only "positive" language. Finally, she says that she rarely sees doctors and that she is "very scared" of hospitals, despite exhibiting a comfortable demeanor. <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=6813>

**"Don't blame the middle man": An exploratory qualitative study to explore the experiences of translators breaking bad news**

*JOURNAL OF THE ROYAL SOCIETY OF MEDICINE* | Online – 18 March 2014 – Major themes [that emerged in this study] included the significant emotional impact of translating distressing information, the challenges of accurately conveying information in a culturally congruent format and the need for formal briefing, debriefing and support. Sub-themes included feeling guilty for divulging distressing news, being the focus of patients' distress or anger, and feeling in conflict with the patient or family and issues surrounding confidentiality. They also felt a strong sense of advocacy for the patients and found encounters with death and dying emotionally challenging. <http://jrs.sagepub.com/content/early/2014/02/26/0141076814527275.abstract>

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**Quotable Quotes**

*If you do unto others as you would have them do unto you, you are making yourself the measure of what is good and right. What you should be doing is thinking about other people and what their needs and interests and desires are. Consider their individuality – and try to respect that. Take into account what might be very different from how you view things, your beliefs and values. Anon*

Of related interest:

- *BRITISH JOURNAL OF HEALTH PSYCHOLOGY* | Online – 15 March 2014 – **'Patients' experiences of an initial consultation in oncology: Knowing and not knowing.** [In this analysis] patients' experiences of being given their diagnosis differed both between participants and within the same participant. Various defences seemed to be used in order to protect them from fully engaging with the knowledge they were given. Their accounts of what they wished to know in the consultation could be affected by a desire to protect themselves and/or family members from distress and by the practical need to know that may vary over time. <http://onlinelibrary.wiley.com/doi/10.1111/bjhp.12096/abstract;jsessionid=0C6292C1D5D7145F92EFE4FDFAA8B22F.f02t03?deniedAccessCustomisedMessage=&userIsAuthenticated=false>
- *THE HASTINGS REPORT*, 2014;44(2):22-25. **'Making treatment decisions for oneself: Weighing the value.'** This emphasis on respect for patients' autonomy may seem to imply that allowing patients to make their own decisions should always take precedence over other considerations. Given this presumption, there has been almost no discussion in the medical literature or elsewhere about how important this value is and whether it should sometimes be balanced against and give way to other values. This absence of guidance is especially problematic in cases where respect for patient autonomy conflicts with promoting patients' clinical interests. <http://www.thehastingscenter.org/Publications/HCR/Detail.aspx?id=6811>

### **Suicide prevention training program for gatekeepers working in community hospice settings**

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE*, 2014;10(1):95-105. Gatekeepers in community hospice settings encounter patients and caregivers struggling with suicidal thoughts. Limited guidance is available for training staff on the prevention of suicide in hospice care. This study evaluated one promising, evidence-based, suicide prevention program with a behavioral rehearsal practice session. Satisfaction and the need for additional devoted time for suicide prevention training were highly rated [by study participants]. Suicide prevention training programs can enhance self-efficacy, knowledge, and skills for gatekeepers working in community hospice settings. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.877865>

Noted in Media Watch, 17 March 2014, #349 (p.16, under 'Worth Repeating'):

- *PALLIATIVE MEDICINE*, 2006;20(7):703-710. **'Responding to desire to die statements from patients with advanced disease: Recommendations for health professionals.'** Given the lack of guidelines to assist health professionals with this issue, the authors prepared multidisciplinary recommendations for responding to a "desire to die" statement, underpinned by key principles of therapeutic communication and a systematic review of empirical literature. <http://pmj.sagepub.com/content/20/7/703.abstract>

### **End of life, chronic illness, and trans-identities**

*JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE* | Online – 14 March 2014 – In this study, the experiences and needs of a sample of 1,963 current, global, English-speaking, transgender-identified adults responding to the Transgender MetLife Survey as related to a number of later-life and end-of-life (EOL) preparations and concerns were examined. EOL concerns are integrated with concerns and challenges around chronic illness and disability. Overall, this population was significantly ill-prepared for the major legalities and events that occur in the later to EOL time periods. The population was found to harbor significant fears around the future. <http://www.tandfonline.com/doi/abs/10.1080/15524256.2013.877864#.UyhpE6hdX8k>

**N.B.** See Media Watch, 21 May 2012, #254 (p.9) for a listing of articles, reports, etc., on the provision and delivery of end-of-life care for LGBT people.

## **Moving on from *Bland*: The evolution of the law and minimally conscious patients**

*MEDICAL LAW REVIEW* | Online – 11 March 2014 – This article seeks to critically appraise the evolution of the law in regard to withdrawing treatment from MCS [minimally conscious state] patients. The piece begins by explaining the differences between the two conditions of PVS [persistent vegetative state] and MCS and defines the law from the starting point of *Bland* [i.e., *Airedale National Health Service Trust v Bland* (1993)]. From here, the discussion progresses to focus on the challenges that the law has had to face in trying to keep pace with the advancing nature of medical understanding of conditions of the brain and explains how it has responded to these. The narrative then critiques the legal mechanism of best interests as it has been employed in the case law concerning MCS patients to date by analysing the various judicial perspectives on the concept. After addressing both the narrow and wide viewpoints, a conclusion is ventured as to how the balancing of best interests should be approached in respect of future MCS cases. <http://medlaw.oxfordjournals.org/content/early/2014/03/11/medlaw.fwu003.abstract>

## **Research with bereaved families: A framework for ethical decision-making**

*NURSING ETHICS* | Online – 10 March 2014 – The authors present a framework for ethical decision-making that has been successfully developed in the context of research with bereaved families. Practical strategies of relevance to the processes of participant recruitment, the interview encounter, and follow-up care in the post-interview period are identified and discussed. The possible impact of bereavement research is balanced with the views of family members who gave credence to the therapeutic and cathartic benefits of participating in sensitive, death-related research. <http://nej.sagepub.com/content/early/2014/03/06/0969733014521097.abstract>

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

### **Nurses left confused about end of life care ahead of Liverpool Care Pathway's demise**

*NURSING STANDARD* | Online – 12 March 2014 – A much-criticised end-of-life care framework is still being used at most acute [National Health Service] trusts in England eight months after a government-commissioned review recommended scrapping it.<sup>1</sup> The Liverpool Care Pathway (LCP) was developed by the Marie Curie Palliative Care Institute in Liverpool to introduce the hospice model of care into hospitals and other healthcare settings. Adverse newspaper coverage of the LCP led to the review [that] recommended it should be phased out in England within six to 12 months. With four months to go until the deadline, most trusts have yet to replace the LCP. <http://rcnpublishing.com/doi/abs/10.7748/ns2014.03.28.28.14.s19>

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>

### **Media Watch posted on Palliative Care Network-e Website**

Palliative Care Network-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, exchange of ideas, information and materials. <http://www.pcn-e.com/community/pg/file/owner/MediaWatch>



## "We all talk about it as though we're thinking about the same thing." Healthcare professionals' goals in the management of pain due to advanced cancer: A qualitative study

*SUPPORTIVE CARE IN CANCER* | Online – 15 March 2014 – Unfortunately, several barriers impede successful management of cancer pain including those relating to the assessment and measurement of pain. There is currently no consensus as to what constitutes good pain control or what healthcare professionals are aiming to achieve in the management of pain for patients with advanced cancer. Interviews took place and four main themes emerged: aims of pain management, assessing response to pain management, managing expectations, and building relationships. Healthcare professionals found assessing patients' pain challenging and reported that patients had difficulty using numerical rating scales. Healthcare professionals used different terms when talking about managing pain, such as "pain control" but found it difficult to define

these terms. Maintaining patients' function and managing their expectations were described as important. However, it was not always clear whether the patient goals mentioned were voiced explicitly by the patient or assumed by the healthcare professional. <http://link.springer.com/article/10.1007/s00520-014-2191-6#>

### Extract from *Supportive Care in Cancer* article

Healthcare professionals described what they deemed important in the management of pain. The goals they mentioned almost exclusively related to function as opposed to pain scores, but patients' goals and expectations were often not elicited specifically.

Noted in Media Watch, 25 November 2013, #333 (p.11):

- *EPIDEMIOLOGY BIostatISTICS & PUBLIC HEALTH*, 2013;10(4):e8698-1-10. '**Pain management and outcomes in cancer patients: Comparison between oncological and palliative sets of care.**' This study indicates how much oncologists and palliative care physicians differ in managing cancer pain. <http://ebph.it/article/view/8698/8206>

### Assisted (or facilitated) death

Representative sample of recent articles, etc:

- *THE HASTINGS REPORT* | Online – 14 March 2014 – '**Physician assistance in dying: A subtler slippery slope.**' Shortly after discharge, my patient's husband called to inform me that his wife had died suddenly the previous evening. The call was not a surprise. I felt she had silently communicated to me that she was taking matters into her own hands, and the quantity of narcotics I prescribed was enough to be lethal if ingested as a single dose. I was aware that this was a possible and perhaps even likely outcome. I could have limited the drug amount, but this would have required that she return frequently to the clinic. I believed that such restrictions were an affront to her dignity and her autonomy. And she could always stockpile her drugs to achieve the same purpose. In the midst of the ongoing contretemps surrounding the legality of physician-assisted death, there is a grey zone of physician complicity. My action in providing my patient with a potentially lethal quantity of narcotics certainly marks me as an assistant, albeit at a remove, in her suicide. <http://onlinelibrary.wiley.com/doi/10.1002/hast.290/abstract>

Cont.

- *LEGAL STUDIES* | Online – 17 March 2014 – '**Mens rea, motive and assisted suicide: Does the Director of Public Prosecution's policy go too far?**' The issue of decriminalising euthanasia and/or assisted suicide has been the subject of a number of high-profile cases, the most recent of which was the Court of Appeal decision in *R (Nicklinson & Lamb) v Ministry of Justice* [2013]... This paper will focus on the offence of assisted suicide and Martin's argument that the Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide, issued by the Director of Public Prosecution following the House of Lords' final judgment in *R (Purdy) v DPP* ... failed to provide foreseeability where a prospective assister was not someone with an emotional connection to the requester. The success of this claim offers a fresh opportunity to examine a somewhat neglected aspect of the Policy that emanated from the Purdy case, namely its potential challenge to the oft-stated claim that motive is irrelevant to *mens rea* [i.e., guilty mind]. <http://onlinelibrary.wiley.com/doi/10.1111/lest.12047/abstract>

Noted in Media Watch, 9 December 2013, #335 (p.14):

- *END OF LIFE JOURNAL*, 2013;3(4). '**The judgment of the High Court [of England] in two right-to-die cases.**' This article summarises the judgment from the High Court cases of Tony Nicklinson and 'Martin.' Both suffered from locked-in syndrome secondary to catastrophic physical disabilities, but their mental processes were unimpaired. <http://endoflifejournal.stchristophers.org.uk/legal-discussions/the-judgment-of-the-high-court-in-two-right-to-die-cases>

## Worth Repeating

### **Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction**

*CRITICAL CARE MEDICINE*, 2004;32(7):1484-1488. Family members of critically ill patients report dissatisfaction with family-clinician communication about withdrawing life support, yet limited data exist to guide clinicians in this communication. The authors of this study identified family conferences in intensive care units of four Seattle hospitals during which discussions about withdrawing life support were likely to occur. Participants were 214 family members from 51 different families. There were 36 different physicians leading the conferences, as some physicians led more than one conference. The mean conference time was thirty-two minutes... On average, family members spoke 29% and clinicians spoke 71% of the time. Increased proportion of family speech was significantly associated with increased family satisfaction with physician communication [and] with decreased family ratings of conflict with the physician. There was no association between the duration of the conference and family satisfaction. This study suggests that allowing family members more opportunity to speak during conferences may improve family satisfaction. [http://journals.lww.com/ccmjournal/Abstract/2004/07000/Family\\_satisfaction\\_with\\_family\\_conferences\\_about.5.aspx](http://journals.lww.com/ccmjournal/Abstract/2004/07000/Family_satisfaction_with_family_conferences_about.5.aspx)

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